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14. ABSTRACT Breast cancer survivors are at elevated risk for developing a new breast cancer compared to healthy women, and are at considerable risk for breast cancer recurrence. According to the American Society of Clinical Oncology, survivors should undergo careful breast cancer surveillance including annual mammography and breast self-exam. However, studies indicate that breast cancer surveillance among African American survivors, particularly mammography, is low, especially given the higher risk of survivors as a group. The promotion of breast cancer surveillance among African American survivors is an area that deserves special attention as cancers detected early are more treatable. The primary objective of the current study is to test the impact of a DVD intervention among 120 African American breast cancer survivors by comparing 2 randomized groups at baseline and 3-month follow-up					
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I. INTRODUCTION

Breast cancer survivors are at elevated risk for developing a new breast cancer compared to healthy women, and are at considerable risk for breast cancer recurrence. According to the American Society of Clinical Oncology, survivors should undergo careful breast cancer surveillance including annual mammography and breast self-exam. However, studies indicate that breast cancer surveillance among African American survivors, particularly mammography, is low, especially given the higher risk of survivors as a group. The promotion of breast cancer surveillance among African American survivors is an area that deserves special attention as cancers detected early are more treatable. One promising strategy is the adaptation of a peer-led intervention developed to increase screening among healthy African American women.

The original objectives of the current study were to: 1) evaluate the impact of a peer-led intervention on breast cancer surveillance intention and adherence among African American breast cancer survivors through a randomized controlled trial; and 2) investigate the mediational pathways through which the peer-led intervention impacts surveillance intention and adherence. It was proposed that 409 participants would be recruited and randomized over the course of the study. It was proposed that participants be African American women age 20-74 years and diagnosed with Stage I, II or III breast cancer who previously participated in an ongoing parent project and are at least 3 months post-treatment. Participants were to be assigned to either a survivor surveillance intervention condition or control condition. Under a revision of the Statement of Work, the objective of the study was revised to test the impact of a DVD intervention among 120 African American breast cancer survivors by comparing 2 randomized groups at baseline and 3-month follow-up

II. BODY

The research accomplishments associated with each task outlined in the approved Statement of Work are as follows:

A. Months 1-17 (June 2003 – October 2004)

- 1. Challenges to project implementation:** The performance period began June 2003 and the study was approved by the IRB and Mount Sinai School of Medicine (MSSM) around this time. However, due to the link between the current grant and a DOD-funded parent study also awaiting approval (“Behavior, Estrogen Metabolism, and Breast Cancer Risk: A Molecular Epidemiologic Study” HSRRB Log Number A-10862.5), DOD IRB approval for the current study was not received until November 2004.
- 2. Staffing:** A full-time project coordinator was hired and trained.
- 3. Collaboration with co-investigators:** Weekly investigator meetings were established that included the PI, the project coordinator, and co-investigators (Dana Bovbjerg, Ph.D., Heiddis Valdimarsdottir, Ph.D., and Lina Jandorf, M.A.). These meetings focus on intervention development and implementation issues, as well as assessment strategies.
- 4. Intervention development:** During this period, “Survivors in Spirit (SIS): Looking Ahead to Life After Breast Cancer Treatment” was developed. This intervention was peer-led and intended to be implemented by two types of peer interventionist: 1) survivor speakers, or African-American breast cancer survivors who share their personal stories of breast cancer diagnosis, treatment, and follow-up care post-treatment, and 2) lay health educators, African American women who may or may not have a diagnosis of breast cancer who present didactic information about breast cancer recurrence risk, surveillance guidelines, and breast self-examination.

SIS intervention content and its training curriculum were developed based on an extensive literature review as well as through the input of an advisory board that included of physicians, breast cancer survivors, patient advocates and health educators. The members of this advisory board are presented in Appendix A. Appendix B presents the information included on a flipchart, reviewed by the advisory board, that was used as a teaching tool as part of SIS presentations.

Another critical step in developing the Survivors in Spirit (SIS) intervention content was the completion of a small qualitative study of 10 African American breast cancer survivors in order to identify factors that support and deter participation in post-treatment breast cancer surveillance and follow-up care. This work (approved by the IRB of Mount Sinai School of Medicine) was presented as a poster titled, “Factors Influencing Post-Treatment Breast Cancer Surveillance among African-American and African-Caribbean Breast Cancer Survivors: A Qualitative Approach.” This poster was presented at the Second Biennial Cancer Survivorship NCI/ACS Research Conference on Cancer Survivorship: Pathways to Health After Treatment in June 2004 (see Appendix C).

5. **Interventionist training:** Appendix D includes a Powerpoint presentation that is used to train SIS’ peer interventionist. During this period, 23 interventionists were trained: 15 lay health educators and 7 survivor speakers, as well as 1 interventionist who was trained to serve in both roles.
6. **Assessment and Data Management:** During this time period, the investigators finalized the assessment (see Appendix E)

Time 1- Part 1 (baseline): Sociodemographics/Medical History/Physician Specialty and Background; Mammography Adherence, Attitudes, Norms, Intention & Behavioral Control; Physical Examination Adherence, Attitudes, Norms, Intention & Behavioral Control; Symptom History Adherence, Intention, and Behavioral Control; BSE Adherence, Intention, and Behavioral Control; Pelvic Exam/Pap Test Adherence, Intention, and Behavioral Control; Other Follow-up Tests and Care; Surveillance Behavioral Beliefs; Surveillance Social Influence/Normative Beliefs; Breast Cancer Recurrence/Surveillance Knowledge; Perceived Breast Cancer Recurrence Risk; Ethnic Identity; Impact of Events Scale; Perceived Access to Healthcare; Genetic Testing Awareness and Interest.

Time 1- Part 2 (baseline): Spirituality; Group-Based Medical Mistrust/Trust in Physician; Participatory Decision Making; Concerns About Recurrence Scale

Time 2 (1-month follow-up): Mammography Adherence, Intention and Physician Recommendation; Physical Exam Adherence, Intention, and Behavioral Control; Symptom History Adherence, Intention, and Behavioral Control; BSE Adherence, Intention, and Behavioral Control; Pelvic Exam/Pap Test Adherence, Intention, and Behavioral Control; Other Follow-up Tests and Care; Breast Cancer Surveillance Attitudes; Social Influence/Norms; Breast Cancer Recurrence/Surveillance Knowledge; Perceived Breast Cancer Recurrence Risk; Genetic Testing Awareness and Interest.

Time 3 (14-month follow-up): Section 1. Breast Cancer Surveillance Adherence and Intention; Other Follow-up Tests and Care; Impact of Events Scale; Exposure to Mammography-Related Information

Additionally, systems for participant tracking (ACCESS) and data entry (SPSS) were developed.

B. Months 18 - 32 (November 2004 – January 2006)

1. **Challenges to project implementation:** Although the performance period began June 2003 and was approved at MSSM, DOD IRB approval was not received until November 2004.
2. **Staffing:** During this period, there was staff turnover. A new full-time project coordinator as well as a part-time research assistant were hired and trained.
3. **Collaboration with co-investigators:** Monthly investigators meetings were held that included the PI, the project coordinator, and co-investigators.
4. **Interventionist training:** Four additional interventionists were trained: 2 survivor speakers and 1 lay health educator. Appendix F includes an abstract describing the training of peer interventionists that was presented at the 2005 Era of Hope conference in Philadelphia, PA.
5. **Recruitment and data collection:** The database of the parent project to identify eligible breast cancer patients. During this period, a total of 29 women agreed to participate. Of these women, 13 were assigned to the intervention condition and 14 were assigned to the control condition. All of these women completed baseline interviews. Of the 27 participating women, 21 completed one-month follow-up interviews.

C. Months 33-48 (February 2006 – May 2007)

1. **Challenges to project implementation:** Amendments to expand recruitment strategies were proposed April 2006 and approved by DOD IRB in December 2006.
2. **Staffing:** By the end of this period, the project coordinator and research assistant left the project due to limited funding.
3. **Collaboration with co-investigators:** During this period, meetings with investigators were phased out due to limited funding.
4. **Interventionist training:** By this time, the research team had conducted 5 five-hour group training sessions (followed by dozens of hours of small group and individual coaching). In total, 33 peers were trained (20 lay health educators, 13 survivor speakers). The impact of this training was demonstrated by increases in knowledge scores (pre-test mean=59%; post-test mean=78%. Also, evaluations of training session quality were extremely positive. Of 11 aspects of training, 9 received highest possible rating from $\geq 90\%$ of trainees
5. **Recruitment and data collection:** Expand recruitment strategies via outreach to New York Hospital Queens and Kings County Hospital (Brooklyn). As part of this effort, site PIs were identified, IRB approvals were obtained at both sites, and the study team collaborated with site PIs to review patient charts and tumor registries to identify potential patients. The study team also collaborated with other MSSM studies to promote individual referral from other sites. By this data, data for 61 women were collected.
6. **Publications:** A manuscript titled, “Posttreatment Breast Cancer Surveillance and Follow-up Care Experiences of Breast Cancer Survivors of African Descent,” was published in Cancer Nursing in 2006 (see Appendix G).

D. Months 49 - 60 (June 2007 – May 2008)

1. Challenges to project implementation: In June 2007, a one-year no-cost extension was granted. April of 2008, a change to the SOW was approved. The change in SOW was requested for the following reasons:

- a. Resources absorbed by unplanned expansion of recruitment strategies:** Due to delays in study start-up, it became necessary to expand recruitment strategies. Initially, recruitment was based on a DOD-funded MSSM-based parent study. However, it became apparent that this project would not suffice as the exclusive referral source since it 1) its enrollment rate was lower than expected and 2) the study only recruited newly diagnosed patients, resulting in a substantial lag-time as the current grant requires that a patient be at least 3 months post-treatment. Recruitment strategies for the current study were expanded by identifying opening protocols at two local hospitals: New York Hospital Queens and Kings County Hospital Center. This demanded a significant allocation of the study's human resources in order to navigate the IRBs of these hospitals as well as work with site PIs and staff to identify potential patients. Recruitment strategies were also expanded by integrating efforts with two other research studies targeting a similar patient population, which required approximately numerous external visits and presentations at external hospitals, clinics, and breast cancer survivor support groups.
- b. Higher refusal rates than anticipated:** Including our expanded recruitment strategies, 312 survivors were identified as part of the total recruitment pool. Of these, 197 were either ineligible, deferred, death, hospitalization, unable to contact, or otherwise excluded. Of those who were eligible and contacted, there were 53 refusals, resulting in a refusal rate of 46%
- c. Low SIS intervention attendance:** In total, 62 women were agreed to participate in the study and 1 was dropped from baseline analyses. There were 32 in intervention group and 29 in control group. Between 2004 and 2007, 12 SIS programs were scheduled. However, only 21 participants attended interventions, resulting in a no-show rate of 34%. We were not able to increase the intervention rate even after applying certain strategies, including changes in the location of intervention programs, serving refreshments, and including raffles and give-aways. This raised serious concerns about the feasibility and practicality of the intervention.

In order to address the feasibility concerns discussed above, we sought and obtained funding in 2007 through the Susan G. Komen for the Cure Breast Cancer Disparities Research Award to convert the live SIS intervention into DVD format (performance period 9/21/07 – 9/20/09). The aims of this new study were 1) to develop a DVD intervention based on SIS to promote post-treatment breast cancer surveillance among African American breast cancer survivors that is guided by focus group input; 2) to conduct a pilot evaluation of the cognitive and psychological impact of the SIS-DVD intervention using standardized questionnaires; and 3) to disseminate results of the SIS-DVD evaluation via educational seminars targeting African American breast cancer survivors as well as healthcare providers and advocacy groups.

As part of the revised SOW, we proposed to test the impact of the SIS DVD intervention in a small randomized trial to include 120 African American breast cancer survivors by comparing two groups at baseline and 6-month follow-up: 1) participants shown the SIS DVD intervention and 2) participants shown a control health DVD intervention.

- d. Progress on revised SOW:** Two focus groups of African American breast cancer survivors were successfully completed. The purpose of the groups was to provide initial evaluations of initial SIS

DVD content and revisions of the DVD based on the feedback of the first focus group. Six survivors participated in Focus Group 1 and five of these survivors participated in Focus Group 2.

E. Months 61 – 72 (June 2008 – May 2009)

- 1. Challenges to project implementation:** Between June 2008 and January 2009, the PI changed institutions twice, first becoming a faculty member at Memorial Sloan-Kettering Cancer Center, then joining the faculty at Albert Einstein College of Medicine at Yeshiva University. In weighing the advantages and disadvantages of moving the current grant, the PI decided to leave the grant at MSSM, where she remained an adjunct faculty member. However, there were numerous challenges in actually utilizing funds managed by MSSM. Formal objection to this arrangement was made by the director of MSSM's Grants and Contracts Office in March 2010 who informed the PI that MSSM "was uncomfortable with being responsible of the oversight" of disbursement of funds at another institution and ordered the study closed.

Additionally, the SIS DVD was not finally completed until November 2009. The PI received a no-cost extension through March 2011 in order to accommodate delays in DVD production

- 2. Progress on revised SOW:** Like the original peer-led SIS program, the SIS DVD is based on the American Society of Clinical Oncology's (ASCO) guidelines for follow-up care and screening after breast cancer treatment. Mirroring the original SIS intervention, the DVD includes 6 didactic chapters: 1) Facts about Breast Cancer Recurrence; 2) Factors that Influence Breast Cancer Recurrence; 3) ASCO Guidelines; 4) Breast Self-Examination (BSE) Instruction; 5) Your Family History of Breast Cancer and Breast Cancer Genetics; and 6) Factors that Influence Participation in Post-Treatment Surveillance. Each didactic chapter is presented by actual African American breast cancer survivor and is 5-8 minutes in length. Images were selected to support and enhance learning within each section and selected medical terms used in the DVD are defined in a glossary list provided as a separate chapter in the DVD. There is also a separate non-narrated chapter presenting local resources related to post-treatment surveillance (e.g., access to low-cost and no-cost healthcare) and breast cancer survivorship in general. In addition to the six didactic chapters presented by survivors, there are six additional "bonus sections" in which each survivor shares her personal story or narrative. Furthermore, brief segments of these narratives precede each didactic chapter as a form of introduction to the chapter's topic. In addition to the six didactic chapters presented by survivors, there are six additional "bonus sections" in which each survivor shares her personal story or narrative. Brief segments of these narratives precede each didactic chapter as a form of introduction to the chapter's topic.

An evaluation of the SIS DVD is ongoing. The following results are based on 9 African American breast cancer survivors have participated in this evaluation, which includes a baseline interview and a follow-up interview immediately after viewing the DVD. All participants were within a 3-year window following treatment completion. The mean age of participants is 61 years (range: 50-70 years). The majority completed high school and reported some college or a college degree and 100% reported having some type of health insurance. Awareness of breast cancer recurrence was moderate, with 57% reporting that they had heard a fair amount or a lot about breast cancer recurrence and how to find a breast cancer recurrence. However, 71% reported that they had heard nothing or little about symptoms of breast cancer recurrence and 57% reported that they had heard nothing or little about guidelines for breast cancer screening after treatment. Similarly, 71% had heard almost nothing or little about genetic testing for breast cancer risk. Participants completed a 14-item knowledge scale at baseline and follow-up. The mean percent correct at baseline was 61% and increased to 83% at follow-up following SIS DVD viewing. Participants were also asked to evaluate the DVD. In this group, 100% said it was excellent or very good. Further, 100% gave the strongest endorsement ("a lot") that the DVD

reflected their culture, was relevant to them as African American breast cancer survivors, had language that was easy to understand, looked professional, presented information in a way that was easy to follow, included personal stories that were relevant to their own experience, and that they trusted the information in the DVD.

3. **Publications:** A manuscript describing the development of the SIS curriculum and training of peer interventionists was published in Cancer Education in 2009 (see Appendix H).

F. Results: The following results are primarily descriptive due to the relatively small number of participants enrolled in the study.

1. **Sociodemographics/medical history/physician specialty:** The mean age of the sample was 55 years (range: 35- 78 years). Table 1 presents other sociodemographic characteristics of participants. About half reported current employment. Approximately 40 % reported a high school degree or less education and a similar proportion reported a household income of less than \$20K per year. The majority of the sample reported some type of health insurance coverage. In terms of breast cancer treatment, the majority reported a combination of surgery (mastectomy or lumpectomy) and adjuvant therapy (radiotherapy or chemotherapy. Eighty-two percent had completed primary treatment less than three years prior to study enrollment. Figure 1 shows the types of physician patients reported seeing for surveillance and follow-up care. The majority of the sample reported contact with a primary care physician for post-treatment care. Eighty-five percent agreed that they were satisfied with the follow-up care they receive.
2. **Baseline Adherence to Surveillance Guidelines:** Figure 2 shows the rates of adherence to mammography, physical Examination, and pelvic exam/Pap test based on ASCO guidelines. Enrolled participants reported high adherence to ASCO guidelines at baseline. In our sample, 93.4% were adherent to mammography guidelines (32% reported at baseline that they had an upcoming appointment for a mammogram). According to our statistical consultant, with a base rate of 93%, a sample size 552 women would be required to observe a 3% increase in mammography use (93% to 96%). About 87% reported adherence to physical exam (49% reported that they had an upcoming appointment for a physical exam at baseline). Observation of a 3% increase in adherence to physical exam (from 87% to 90%) would require a sample size of 1035. Finally, 77% reported adherence to pelvic exam/pap test (23% reported an upcoming appointment at baseline). For a 4% increase in these tests (77% to 81%), a sample of 1059 women would be required.
3. **Randomization to study arms:** As described above, 31 participants were randomized to the intervention arm and 29 to the control arm. However, only 21 participants in the intervention arm actually attended an intervention. Of these, only 15 completed the Time 2 assessment. In the control group, only 21 completed the Time 2 assessment. Therefore, longitudinal analyses comparing the groups are based on an n of 36.
4. **Breast cancer recurrence and surveillance knowledge:** Table 3 shows the percentage of the total baseline sample that answered each knowledge item correctly. Table 3 also shows the percentage of the longitudinal sample that answered each knowledge item correctly at both baseline and Time 2. Overall, there was a slight but non-significant increase in knowledge from baseline (53.9%) to Time 2 (55.3%). The intervention group demonstrated a change score of 4.0 (overall increase) while the control group had a change score of -0.47 (overall decrease). However, this difference was not statistically significant.

5. **Variables outlined in Theory of Planned Behavior:** Participants also demonstrated high baseline scores on the mediating variables outlined in the proposal via the Theory of Planned Behavior. Participants completed a 27-item measure of attitudes or breast cancer surveillance behavioral and control beliefs. The measure had strong reliability ($\alpha=.83$). The mean attitudes score in the total sample was 1.99 ($SD=.53$) (possible range: 1-5; lower scores mean more positive attitudes). Participants also completed a 12-item measure of social norms related to post-treatment breast cancer surveillance. This measure also had strong reliability ($\alpha=.89$). The mean norms score in the total sample was 4.2 ($SD=.84$) (possible range: 1-5; higher scores mean greater perception of norms supporting surveillance). Perceived behavioral control over participating in surveillance was also high. At baseline, 78.7%, 73.8%, and 78.3% reported a lot or complete control over getting their next mammogram, physical exam, and pelvic exam/Pap test, respectively. Finally, 78.9%, 81.9%, and 91.7% agreed that they reported that the intended to have a mammogram, physical exam, and pelvic exam/Pap test, respectively, within the recommended time period. These score reveal that attitudes, perceived norms, perceived behavioral control, and behavioral intention among participants were already high at baseline and possibly reflect a ceiling effect with most scores within the upper limits of these measures.
6. **Evaluations of the SIS intervention:** One-hundred percent of attendees reported that the SIS presentations were well-organized; the presenters knew what they were talking about; the presenters spoke in ways I could understand, they felt good about their ability to use what they learned; and that the personal testimonies of survivors were a very important component of the presentation. Furthermore, 95% rated the inclusion of Black women as presenters and in materials as very important.

III. KEY RESEARCH ACCOMPLISHMENTS:

- Development of a peer-led intervention promoting post-treatment breast cancer surveillance (Survivors in Spirit; SIS).
- Development of a curriculum to train laypeople as SIS interventionists.
- Successful training of 33 peer interventionists.
- Highly positive evaluation of the SIS intervention by study participants.

IV. REPORTABLE OUTCOMES:

- A. **Manuscripts:** As described above, two manuscripts were published describing intervention development (see Appendix G) and interventionist training (see Appendix H).
- B. **Additional funding:** As a result of work supported by this award, the PI successfully a two-year disparities research award from Susan G. Komen for the Cure (DISP0707116: “Promoting Breast Cancer Surveillance among African American Survivors.”).

- V. **CONCLUSIONS:** The original goal of this research study was to develop and test an “in-person” intervention to increase post-treatment breast cancer surveillance among African American breast cancer survivors. Across several studies, race/ethnicity was one of the strongest predictors of non-adherence to post-treatment breast cancer surveillance (1), with African American survivors demonstrating a lower likelihood of completing consecutive surveillance mammograms over several years compared to White survivors as well as fewer months of medical follow-up (2) (3). However, successful completion of this study goal was impeded by several factors, including delays in receipt of approvals from the funding agency; unexpected re-direction of resources in order to expand the study and increase the pool of potential participants; high refusal rates; low attendance to the SIS intervention presentations; and high adherence to ASCO guidelines for post-treatment breast cancer surveillance at baseline.

Future work in this area can address some of these barriers. First, refusal rates may be decreased by a different recruitment approach. The current study originally proposed to identify participants through a parent project, a case-control study focusing on molecular biomarkers of disease. The PI's more recent experience with post-treatment surveillance research has demonstrated the value of closer collaboration with treating physicians. Physician involvement in introducing potential participants to the study and/or the study team can play a vital role in minimizing refusals to enroll. Furthermore, the PI underestimated the impact of the potential participant's experience in the parent project. Anecdotal information revealed that a survivor were less likely to enroll in the current study if her experience in the parent project was negative (e.g., she found the assessment to be burdensome, intrusive, or upsetting).

The problem of low attendance can be addressed by presenting the information in other intervention formats. The PI has obtained funding from Susan G. Komen for the Cure to convert the in-person SIS intervention into a DVD. DVDs are familiar and accessible technology as indicated by the recent results of a national survey by the Pew Research Center for the People & the Press reporting that 86% of American households own a DVD player (4). DVDs are interactive (e.g., the survivor can view the DVD in her preferred language, and watch sections of the DVD in whatever order she chooses) and have the advantages of being portable and fairly easy to disseminate in a variety of community and clinic settings. DVDs also overcome some literacy issues in that they tend to largely rely upon visual and auditory modes of communication. Finally, a DVD offers a consistent, standardized way of communicating information about post-treatment surveillance, regardless of setting. Future work may also consider presenting the SIS intervention in other new media platforms, including the internet and mobile phones.

Recent data has provided some insight into the high adherence to ASCO guidelines for post-treatment breast cancer surveillance at baseline. Regardless of race/ethnicity, adherence to guideline surveillance among survivors decreases over time. Two large-scale, multi-site studies have reported steady declines in mammography over the 5-year period following end of treatment, with rates in post-treatment surveillance year (SY) 1 at approximately 80% and between 62-69% by SY 5 (5) (2). In the current study, 82% of participants had completed primary breast cancer treatment <3 years prior to study enrollment. More recent data suggest that future work should ensure that their sampling frame includes long-term survivors as well as more recent ones.

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VII. SUPPORTING DATA

Table 1. Sociodemographics/medical background.

		Total sample (N=61)
Currently employed?	Yes	51.7%
Education	High school degree or less	42.6%
Income	<\$20K	42.9%
Marital status	Married/living with partner	36.1%
Health insurance coverage?	Yes	85.3%
Type of treatment	Surgery (mastectomy or lumpectomy) alone	14.8%
	Surgery plus adjuvant therapy (radiotherapy or chemotherapy)	85.2%

Table 2. Percent correct on knowledge measure.

		% Correct Time 1 (Baseline sample; N=61)	% Correct Time 1 (n=36)	% Correct Time 2 (n=36)
1.	Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	19.7	19.4	16.7
2.	Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	26.2	25.0	30.6
3.	Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	93.4	94.4	97.2
4.	Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	60.7	66.7	55.6
5.	Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	11.5	16.7	16.7
6.	Breast cancer survivors only need to have physical exams about once a year after they have completed breast cancer treatment.	60.7	66.7	72.2
7.	Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	98.3	97.2	97.2
8.	Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	96.7	97.2	94.4
9.	Women diagnosed with breast cancer need to examine their own breasts every day.	42.6	44.4	58.3
10.	Chest pain and problems with breathing can be signs of breast cancer recurrence.	18.0	11.1	13.9
	Total	52.8	53.9	55.3

Figure 1. Physicians seen for surveillance and follow-up.

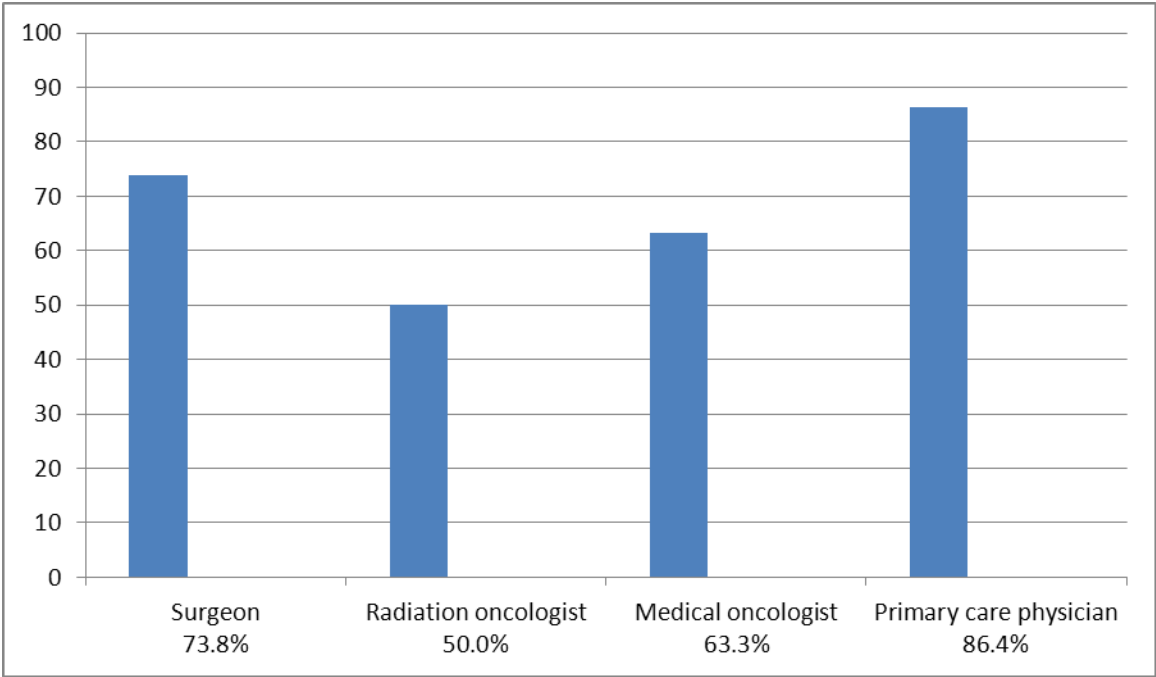
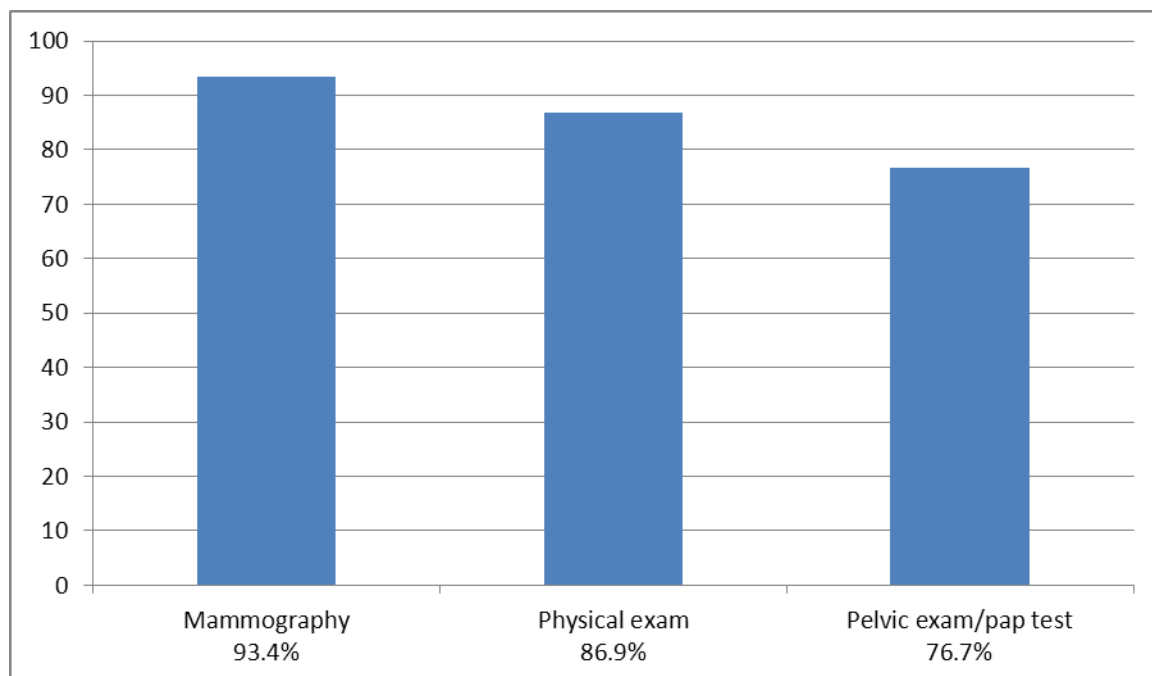


Figure 2. Adherence to ASCO guidelines.



Appendix A

SIS Advisory Board

Eloise Nobles, Witness Role Model, Witness Project of Harlem

Desiree Walker, Witness Role Model, Witness Project of Harlem

Helen M. Webber, Witness Role Model, Witness Project of Harlem

Marilyn Moore, Executive Director, Witness Project of Connecticut

Stephanie Billingsley, Witness Role Model, Witness Project of Harlem

Elizabeth Carde, Lay Health Advisor, Witness Project of Harlem

Susan H. Lee, MD, Breast Surgeon, New York Hospital Queens Breast Center

Dorothy Burch, RN

Alberta Morgan, Lay Health Advisor, Witness Project of Harlem

Reather McAllister, Witness Role Model, Witness Project of Harlem

Jenny Romero, MD, Oncologist, Ralph Lauren Center for Cancer Care/Prevention

Erica Wahl, MS, CGC, Genetic Counselor, Rutenberberg Cancer Center, Mount Sinai School of Medicine

Lina Jandorf, Assistant Research Professor, Rutenberberg Cancer Center, Mount Sinai School of Medicine

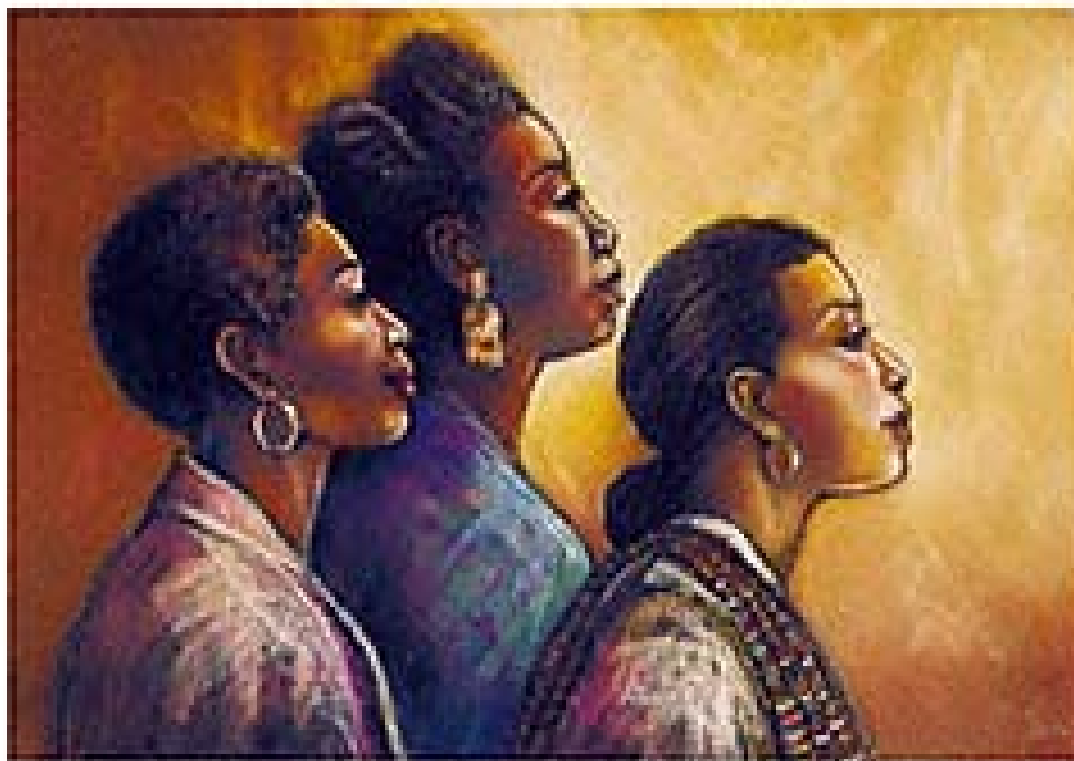
Bert Petersen, Jr., MD, Surgical Oncologist, Beth Israel Medical Center

Vannisha Taylor, Witness Role Model, Witness Project of Harlem

Deborah Bristol, Kings County Hospital

Appendix B

Survivors in Spirit (SIS)



Women Who Look Ahead
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Looking Ahead to Life After Breast Cancer Treatment

Mount Sinai School of Medicine
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Good news about breast cancer survivors

- ❖ There are over 2 million female breast cancer survivors in the U.S.
- ❖ About 160,000 of these survivors are African American or Black.



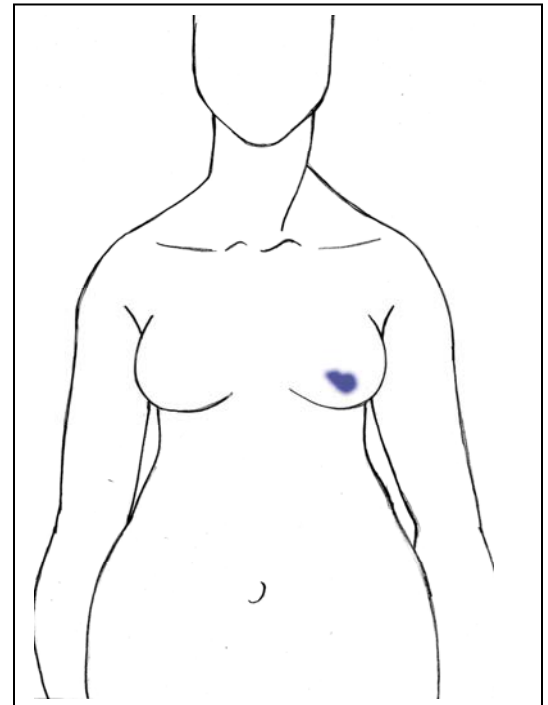
What is a breast cancer recurrence?

- ❖ **The reappearance of a cancer believed to be cured or in remission, developed from cancer cells that were not destroyed by initial cancer treatment.**

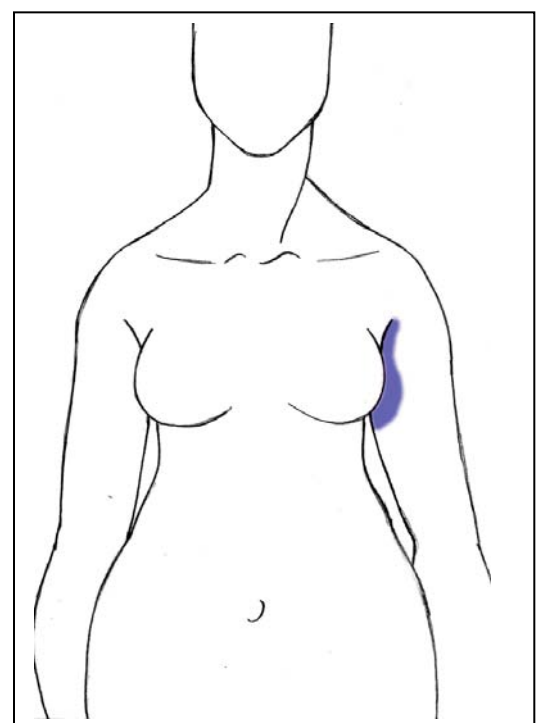
**Not all recurrences
are the same.**

Types of breast cancer recurrence

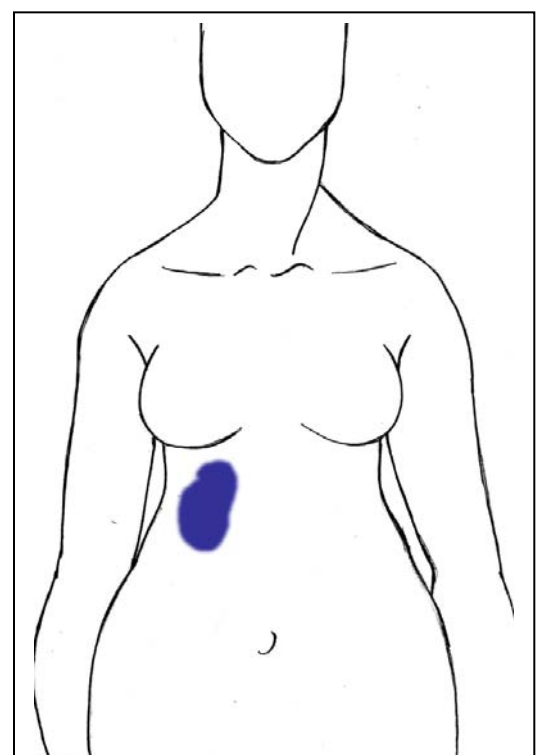
Local recurrence



Regional recurrence



Distant recurrence



How common is breast cancer recurrence?

**Survivors with recurrence at
5-year follow-up**

**Local recurrence:
5-10%**

**Distant recurrence:
about 20%**

**Approximately 70% of
recurrences are identified
within the first 5 years after
diagnosis and treatment.**

Black survivors and recurrence

**Black breast cancer survivors
may have less favorable
recurrences.**

**Black survivors do not
necessarily have higher rates
of recurrence.**



Risk factors for breast cancer recurrence

❖ Age

Younger survivors are at greater risk for breast cancer recurrence

❖ Features of the first breast cancer tumor

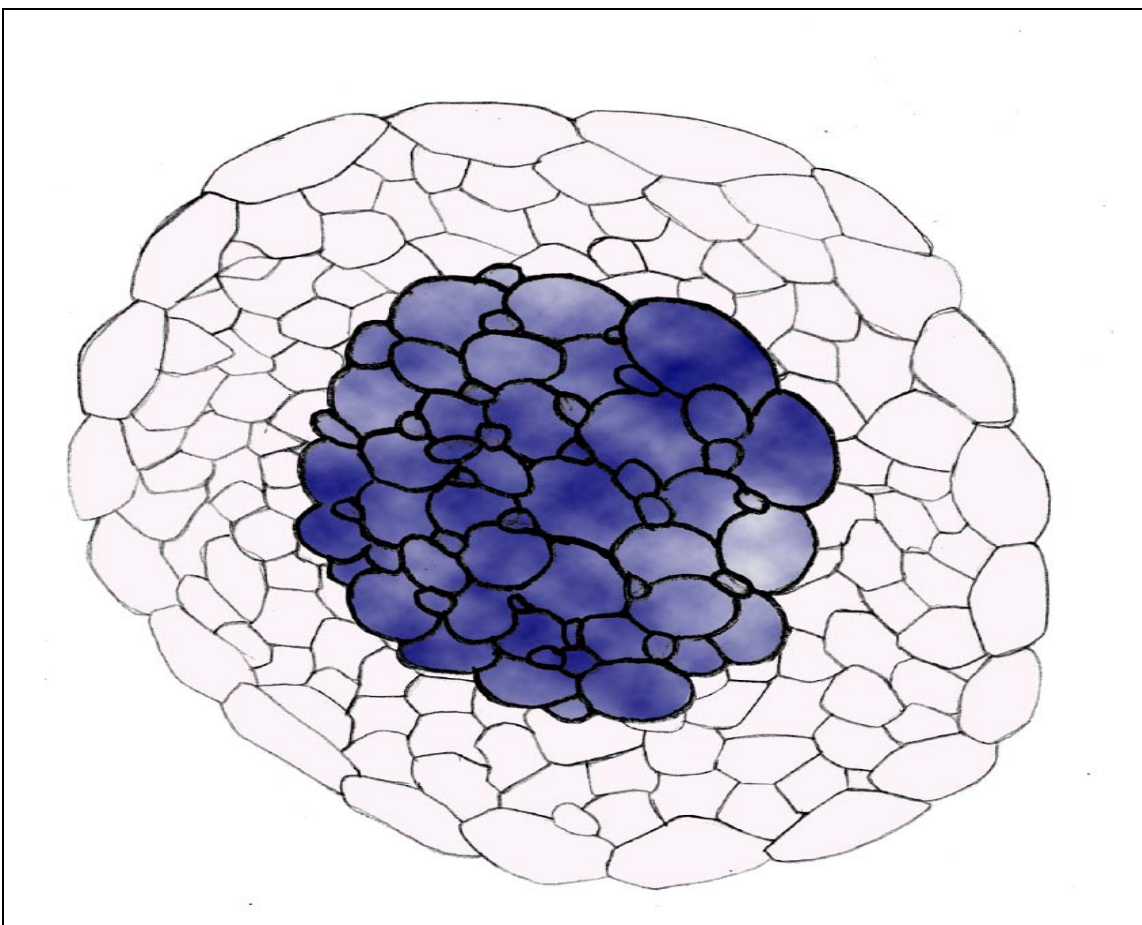
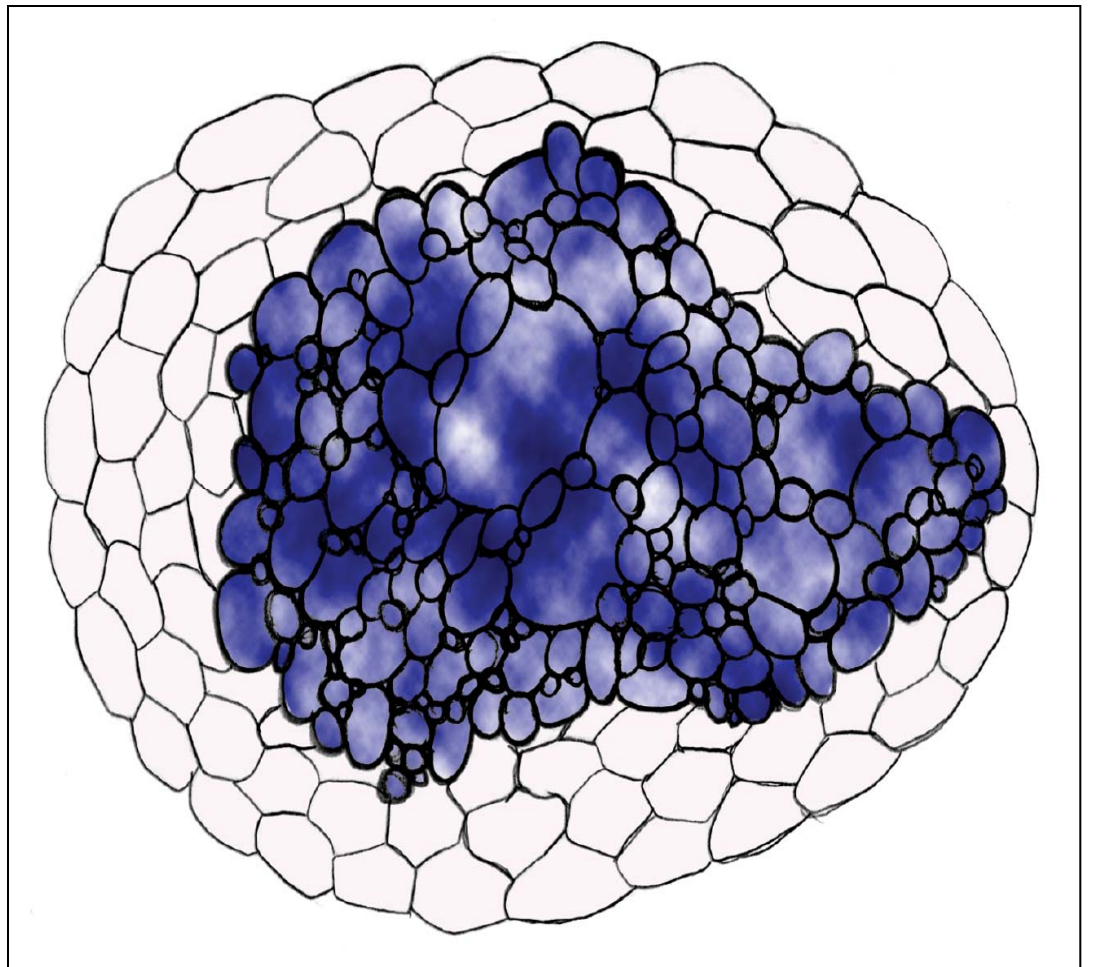
Information about one's tumor is in a pathology report that is part of one's medical records.

Risk factors for breast cancer recurrence

Features of the tumor

1. Positive/close and unclear or unknown resection margins:

**Positive
margins**



**Negative
margins**

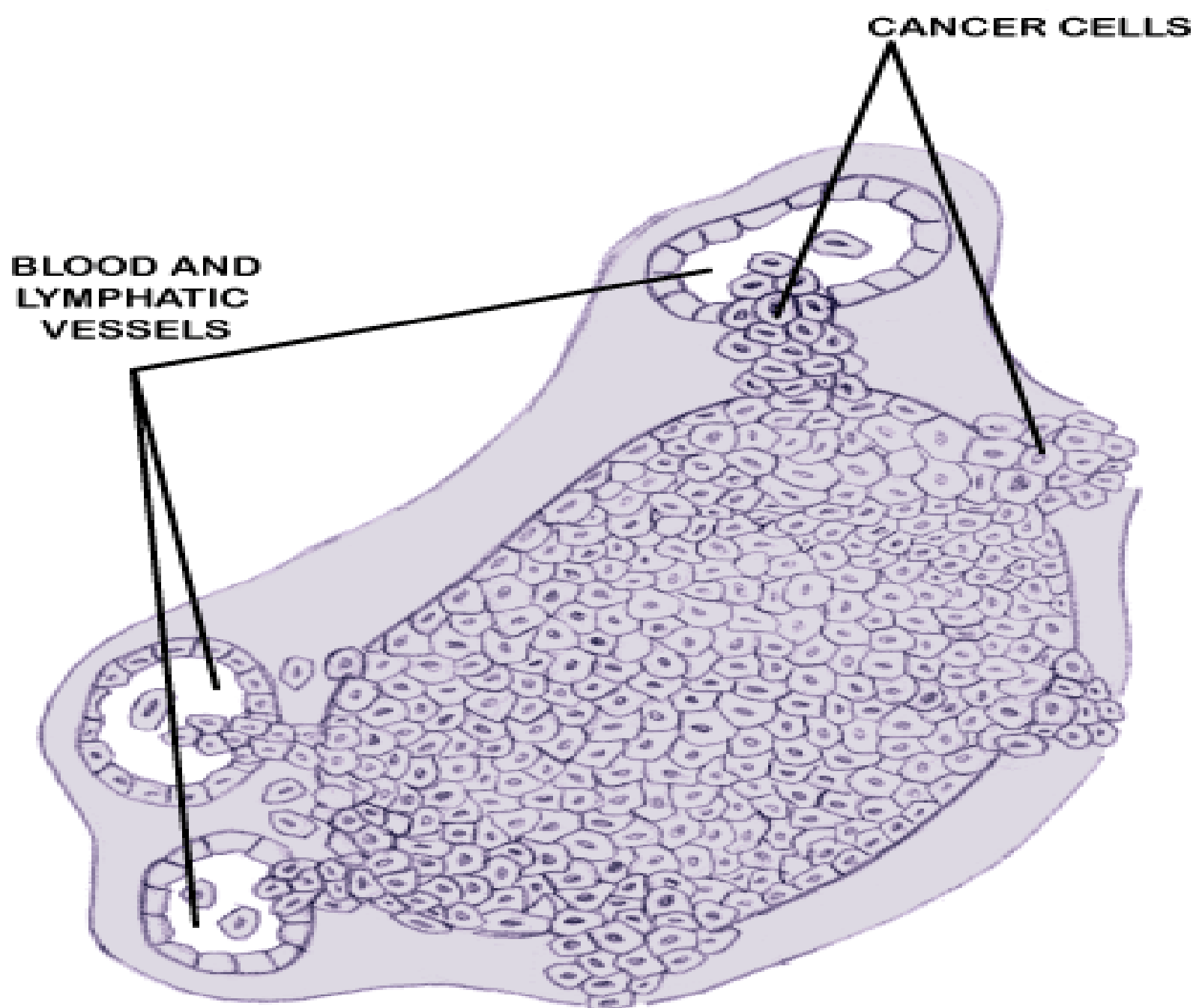
Risk factors for breast cancer recurrence

2. Extent of intraductal cancer (cancer in breast ducts):

The more cancer found in the ducts surrounding the tumor, the greater the risk of recurrence.

Risk factors for breast cancer recurrence

3. Vascular invasion (cancer in blood/lymphatic vessels)



Risk factors for breast cancer recurrence

4. Positive lymph nodes:

The more lymph nodes determined to be positive (cancerous), the greater the chance of recurrence.

Regular follow-up care and screening for breast cancer recurrence

- ❖ Regular follow-up care and screening leads to early detection.
- ❖ Getting regular follow-up care and screening can detect a tumor at an earlier stage and when it is smaller.



American Society of Clinical Oncologists (ASCO) Guidelines

1. A careful physical examination and symptom history

- ❖ **2-4 times a year for the first 3 years**
- ❖ **1-2 times for the next 2 years**
- ❖ **Once a year after that**

2. Annual mammogram

3. Monthly breast self-exam (BSE)

4. Regular pelvic exam and pap test

ASCO Guidelines: Physical exam and symptom history

- ❖ **2-4 times a year for the first 3 years (every 3-6 months)**
- ❖ **1-2 times for the next 2 years (every 6-12 months)**
- ❖ **Once a year after that**

A physical exam can detect a recurrence even if the survivor has no symptoms.

ASCO Guidelines: Physical exam and symptom history

A survivor may not have any symptoms or signs of breast cancer recurrence.

However, about 70% of recurrences are detected by patients, themselves, based on symptoms they notice between routine visits.

ASCO Guidelines: Symptoms of Recurrence

- 1. Any changes in the breast**
- 2. Bone pain or tenderness**
- 3. Chest pain or difficulty breathing**
- 4. Vaginal discharge or spotting**
- 5. Abdominal pain**
- 6. Discomfort, fullness or pain in upper right part of the body**

ASCO Guidelines: Symptoms of Recurrence

7. Persistent headache

**8. Changes in mental
functioning**

9. Problems with movement

**10. Problems seeing or
hearing**

11. Seizures

12. Weight loss

13. Fatigue

ASCO Guidelines

Annual Mammogram

**Monthly Breast
Self-Exam**

**Regular Pelvic
Exam & Pap Test**

ASCO Guidelines

- ❖ **Studies have compared the ASCO guidelines to more extensive testing, such as blood tests, bone scans, CT scans, and MRIs.**
- ❖ **There is no difference between the ASCO guidelines and more extensive testing.**

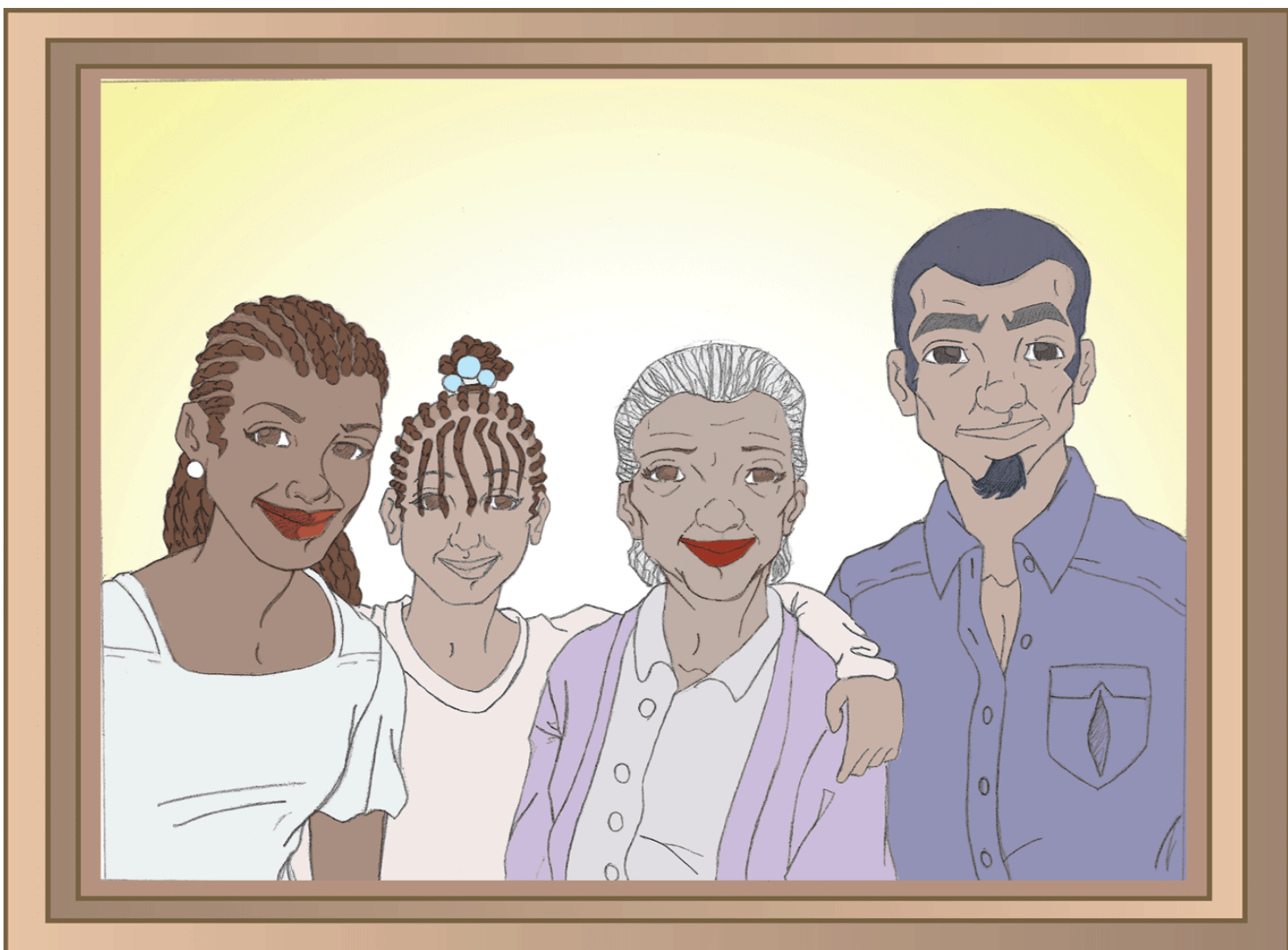
Second primary breast cancer

- ❖ **If a survivor is diagnosed with cancer in the breast that was not originally affected (the opposite breast), this is referred to as**
 - ❖ **A second primary breast cancer**
 - ❖ **A new primary**
 - ❖ **Contralateral breast cancer**

This is a new cancer that is unrelated to the first and is not a recurrence.

Breast cancer genetics

- ❖ **Genes called BRCA1 and BRCA2 control breast cell growth.**
- ❖ **BRCA mutations occur in about 10% of breast cancer survivors and their families**



Breast cancer genetics

Typically in these families:

- ❖ **More than one person has been diagnosed with breast or ovarian cancer**
- ❖ **Family members are diagnosed at younger ages**
- ❖ **Family members may have been diagnosed with cancer in both breasts**
- ❖ **There may be men in the family diagnosed with breast cancer**

Breast cancer genetics

- ❖ **Up to 64% of breast cancer survivors who carry a BRCA mutation develop a second primary breast cancer.**
- ❖ **For a survivor who has a BRCA mutation, the risk of developing ovarian cancer is up to 50%.**
- ❖ **A survivor's chance of developing a recurrence in the same breast is also increased.**

Genetic testing is available to learn if you have a BRCA mutation.

Black survivors and breast cancer genetics

- ❖ **It is unknown if BRCA mutations are more common or less common among Black people compared to other racial/ethnic groups.**
- ❖ **It is known that the chance of an ambiguous or unclear result following BRCA testing is higher among Black people.**

No formal screening guidelines for breast cancer survivors with a BRCA mutation.

Some organizations recommend the same follow-up care and screening as other survivors plus

- ❖ Pelvic exam 1-2 times a year**
- ❖ Vaginal ultrasound 1-2 times a year**
- ❖ Annual serum screening for CA-125, a tumor marker for ovarian cancer**

Survivors with a BRCA mutation may also have surgery that removes the breasts or ovaries to help prevent cancer

Follow-up care and screening among breast

- ❖ **A surprising number of breast cancer survivors do not get adequate follow-up care, regardless of race or ethnic background.**
- ❖ **Black survivors were half as likely to have a mammogram than White survivors in one study.**
- ❖ **The length of follow-up care for Black survivors was significantly shorter than that of White survivors in another study.**

What keeps Black survivors from getting follow-up care?

- ❖ **Lack of knowledge about the recommended guidelines for follow-up care.**
- ❖ **Not asking one's doctor the right questions about follow-up care.**
- ❖ **Fear of being diagnosed with cancer again.**
- ❖ **Avoiding talk or thoughts about cancer because that experience is "over."**
- ❖ **Lack of support from family and friends.**
- ❖ **Costs of medical care.**
- ❖ **Lack of awareness of programs that can help with the costs of care.**

What motivates Black survivors to get follow-up care?

- ❖ **Concerns about being diagnosed again**
- ❖ **Doctors' recommendations, support, care and concern**
- ❖ **Support from one's family**
- ❖ **Desire to survive to spend time with children and grandchildren**
- ❖ **Relationships with other breast cancer survivors**
- ❖ **Spiritual faith**
- ❖ **Desire to live a healthy life**

Take care of yourself!

- ❖ **Be active in managing your stress**
- ❖ **Research does not yet show a consistent link between stress and breast cancer.**
- ❖ **However, we know that stress can affect your immune system and help cause illness.**

Take care of yourself!

The American Cancer Society has diet and exercise guidelines for cancer prevention:

- ❖ Eat a variety of healthy foods, especially fruits and vegetables**
- ❖ Lead a physically active lifestyle**
- ❖ Maintain a healthy weight**
- ❖ Limit the drinking of alcohol**
- ❖ Be aware of food safety**

Breast self-examination (BSE)

During BSE, a woman is looking for any change in the breast

Lumps

Swelling

Dimpling

**Changes in color of skin
(redness or veins become visible)**

Nipple discharge

Rashes

Inverted nipples

Survivors in Spirit is an educational program focusing on Black breast cancer survivors.

The goals of Survivor in Spirit are:

1. To increase awareness about the guidelines for follow-up care after breast cancer treatment among Black survivors.
2. To increase participation in follow-up care among Black survivors.

This is important because breast cancer survivors are at risk for recurrence, which means having the cancer reappear.

Also, a breast cancer survivor is 3 times as likely to develop a new breast cancer compared to a woman who has never had breast cancer.

Unfortunately, it has been reported that Black survivors are not screened regularly compared to White survivors.

It is important that Black survivors have information about regular screening because we know that regular follow-up care can detect a breast cancer recurrence or a new breast cancer at an early stage. Also, cancer found early is better treated and controlled.

Good news about breast cancer survivors



There are over 2 million female breast cancer survivors in the U.S.

About 160,000 of these survivors are African American or Black.

Most women diagnosed with breast cancer survive and do not die of the disease.

However, breast cancer survivors are at higher risk for breast cancer compared to other women never diagnosed.

What is a breast cancer recurrence?

A breast cancer recurrence is the reappearance of a cancer that was thought to be cured or in remission, developed from cancer cells that were not destroyed by the initial cancer treatment.

Not all recurrences are the same.

Types of recurrence

❖ The first type of recurrence is local recurrence

A local recurrence is one that is found in the treated breast after breast-conserving treatment, such as lumpectomy. It may be found in the scar or chest wall after mastectomy

❖ The second type of recurrence is regional recurrence:

A regional recurrence is one found in nearby lymph nodes or other tissues

A regional recurrence may be found in the axillary lymph nodes (in armpits) and/or lymph nodes in the center of the chest and elsewhere near the chest.

❖ The third type of recurrence is distant recurrence:

A distant recurrence is one in which the cancer has spread or metastasized to organs or other tissues far from the breast where it was originally found, such as bone, liver or lungs.

Even if cancer reappears in a part of the body other than the breast, it is considered a breast cancer recurrence because it will usually have the same type of cells as the original tumor.

How common is breast cancer recurrence?

Some large research studies focused on survivors diagnosed with in situ, stage 1 or stage 2 -breast cancer

At 5-year follow-up

5-10% of survivors had a local recurrence

About 20% had a distant recurrence

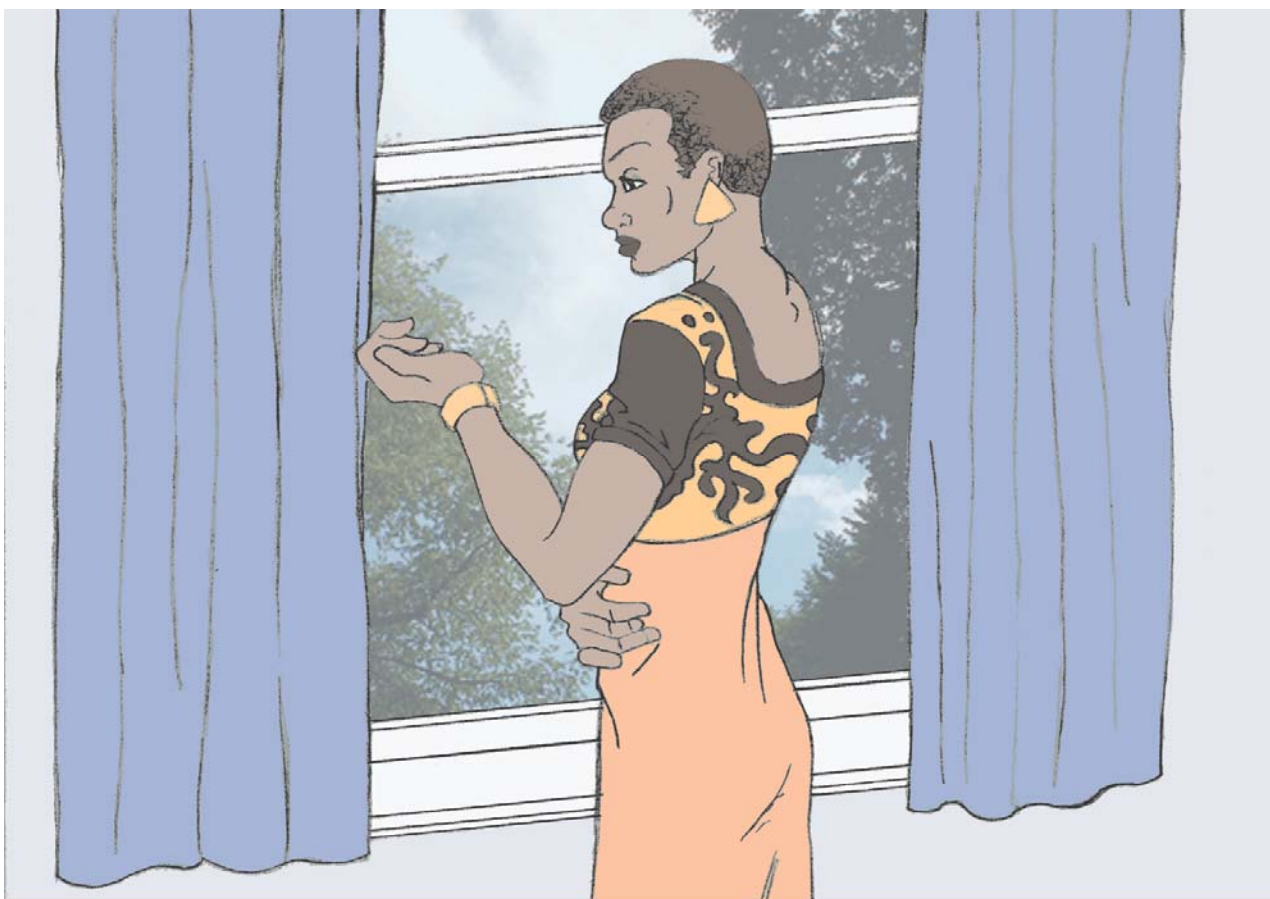
Approximately 70% of recurrences are identified within the first 5 years after diagnosis and treatment.

Careful follow-up care and screening during this 5-year period is essential because a woman can still be a long-term survivor after a local recurrence

Black survivors and recurrence

Black breast cancer survivors may have less favorable recurrences, such as cancers that show more involvement of the skin.

However, Black survivors do not necessarily have higher rates of recurrence compared to other groups.



Risk factors for breast cancer recurrence

A survivor has little control over most of the risk factors for recurrence. However, awareness of risk factors may encourage a woman to work more closely with her doctors in getting follow-up care.

Age is a risk factor for breast cancer recurrence.

Younger survivors are at greater risk for breast cancer recurrence. “Young” means anywhere from 35-50 years old.

Why are younger women at greater risk?

One reason may be that younger women have a longer life expectancy and more time for cancer to recur.

Another reason may be that younger women are less likely to have gone through menopause. They may be at greater risk because there is a relationship between menopause (change of life), hormones and cancer growth.

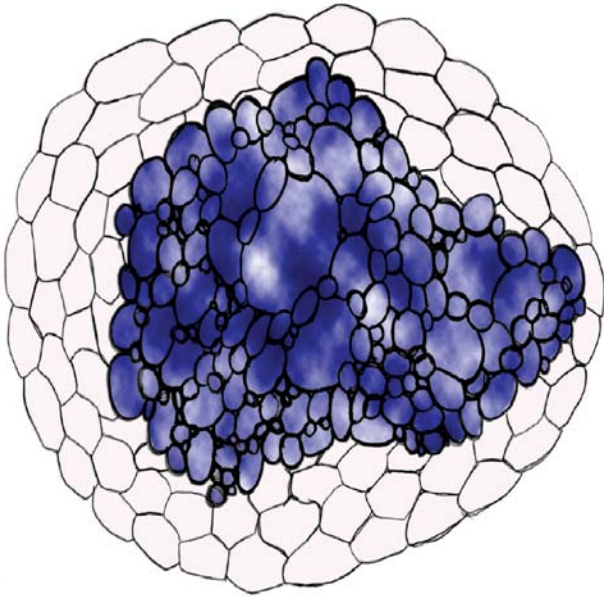
A third reason is that younger women may have more unfavorable cancers to begin with.

Features of the first breast cancer are also risk factors for recurrence.

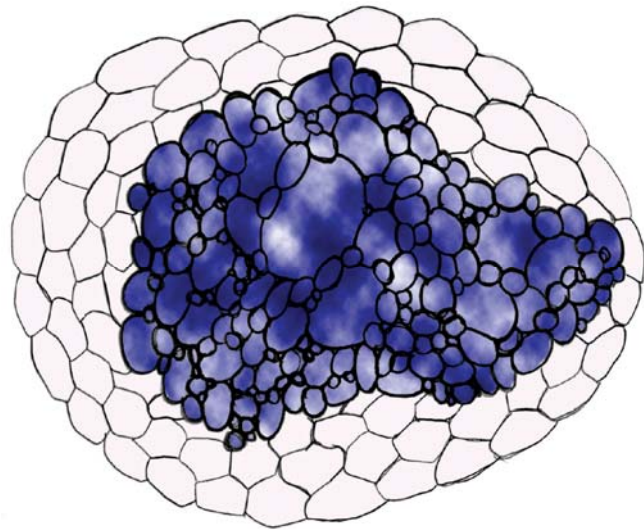
This information is usually in a pathology report that is part of one's medical records.

1. Positive or close resection margins are a risk factor for recurrence:

If cancer is found at the edge of the tumor tissue removed during surgery (or if it is unclear if cancer is at the edge), the risk of recurrence is greater.



**Positive
margins**



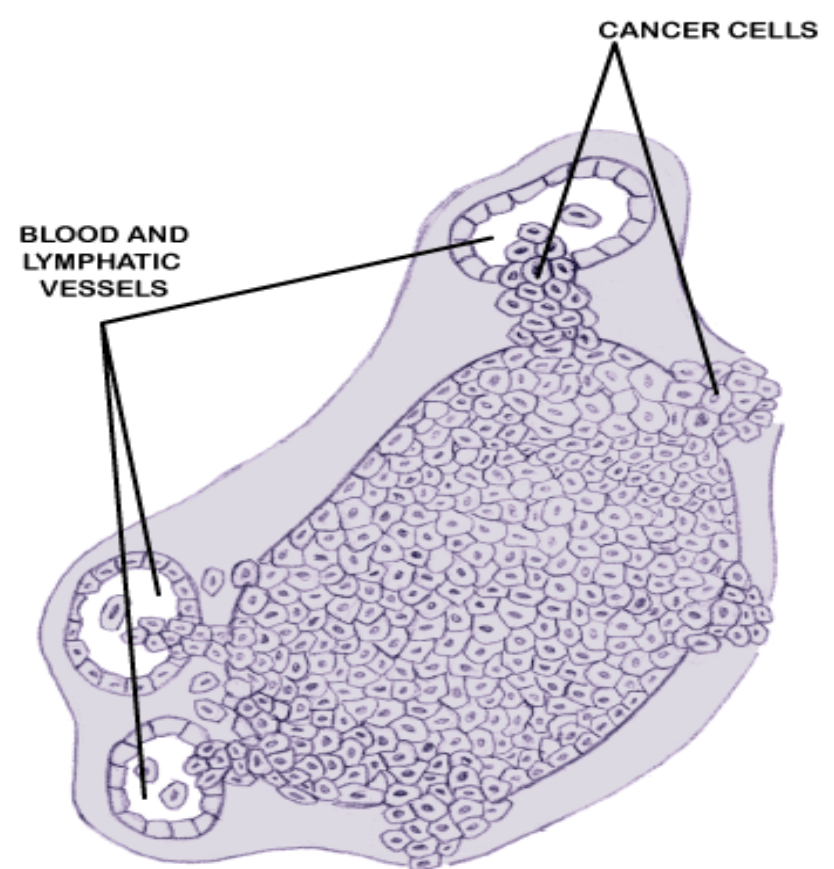
**Negative
margins**

2. A second risk factor is the extent of intraductal cancer (cancer in breast ducts):

The more cancer found in the ducts surrounding the tumor, the greater the risk of recurrence.

3. A third risk factor is vascular invasion (cancer that may be in the blood and lymphatic vessels):

The more that cancer cells have entered the vessels surrounding the tumor, the greater the risk of recurrence.



4. A fourth risk factor is the number of positive lymph nodes:

The more lymph nodes that are found to be positive or cancerous, the greater the chance of recurrence

Regular follow-up care and screening for breast cancer recurrence



Regular follow-up care and screening leads to early detection.

There are benefits to early detection.

For example, getting regular follow-up care and screening can detect a tumor at an earlier stage and when it is smaller

Also, when a survivor detects a recurrence at an early stage, she is more likely to recover.

The American Society of Clinical Oncologists (ASCO) has established guidelines for follow-up care and screening after breast Cancer treatment

The first guideline is a careful physical examination and symptom history

A survivor should have a physical exam 2-4 times a year for the first 3 years

Then 1-2 times for the next 2 years

Then once a year after that

The second guideline is a mammogram every year (with the first one performed 6 months after the end of treatment)

The third guideline is a monthly breast self-exam (BSE)

The last guideline is a regular pelvic exam and pap test

Now, I will discuss each guideline in more detail. First, I will talk about physical exams and symptom histories

It is recommended that a survivor have a physical exam and report her symptoms:

- 2-4 times a year for the first 3 years (that is about every 3-6 months)
- For the next 2 years, a survivor should have an exam 1-2 times a year (that's about every 6-12 months)
- A survivor should then see her doctor at least once a year after that

A physical exam can detect a recurrence even if the survivor has no symptoms.

A survivor may not have any symptoms or signs of breast cancer recurrence.

However, if there are symptoms or problems, talking about them with a doctor is important. About 70% of recurrences are detected by patients themselves based on symptoms they notice between routine visits.

What are the signs and symptoms of breast cancer recurrence?

1. Any changes in the breast maybe a sign of cancer, such as:

- ❖ a lump
- ❖ A rash (The rash could be a sign of a rare type of breast cancer called Paget's disease)
- ❖ swelling
- ❖ dimpling or puckering
- ❖ changes in color of skin (redness or veins become visible)
- ❖ nipple discharge
- ❖ inverted nipples

Other symptoms may be signs that the cancer has spread or metastasized

2. A sign it may have spread to the bone is bone pain or tenderness

3. A sign it may have spread to the lung is chest pain or difficulty breathing

4. Signs of a problem in the uterus include vaginal discharge, spotting or abdominal pain

5. A sign that it may have spread to liver is discomfort, fullness or pain in the right upper part of body

Other symptoms may be signs that the cancer has spread or metastasized

6. Signs that it may have spread to the central nervous system or brain include

- persistent headache (spread to central nervous system or brain)
- changes in mental functioning
- problems with movement
- problems seeing or hearing
- seizures

7. Other general signs that the cancer has spread include weight loss and fatigue

Another follow-up care guideline is a yearly mammogram

The first mammogram should be six months after treatment. It is a baseline mammogram performed once changes due to breast cancer treatment are stable.

After that, a mammogram should be conducted at least once a year

A doctor may order more mammograms based on findings

Another follow-up care guideline is a monthly breast self-exam

Breast self-exam should be performed on both breasts, even if the survivor has had a mastectomy.

In survivors who have had a mastectomy, local recurrence may occur in the chest wall and skin flaps.

Another follow-up care guideline is regular pelvic exam & pap test

A vaginal and rectal examination and pap test is recommended due to the increased risk of cancer in the uterus, especially in women taking tamoxifen.

Women who have had a hysterectomy should consult with their physician as they may be examined less frequently.

Studies have compared the guidelines I have just described to more extensive testing, such as blood tests, bone scans, CT scans, and MRIs.

These studies did not find that more extensive testing was better than the guidelines I have just described.

More extensive testing will not necessarily find a recurrence any faster or extend a survivor's life.

However, the ASCO guidelines represent the minimum follow-up care that a survivor should receive.

A survivor may choose to have more extensive follow-up if she and her doctor decide that is best.

Survivors should also be aware of the risk of a second primary breast cancer

If a survivor is diagnosed with cancer in the breast that was not originally affected (the opposite breast), this is referred to as

- ❖ a second primary breast cancer , or
- ❖ a new primary, or
- ❖ contralateral breast cancer

A second primary is a new cancer that is unrelated to the first and is not a recurrence.

2-11% of survivors may develop a second primary.

At this time, I would like to talk about breast cancer genetics

Genes are in every cell of our bodies and control different functions.

Genes called BRCA1 and BRCA2 control breast cell growth.

BR stands for “breast” and CA stands for “cancer.”



Mutations or changes in the BRCA genes increase the risk of breast and ovarian cancer.

BRCA mutations occur in about 10% of breast cancer survivors and their families.

In these families, breast cancer is “passed down” through generations.

Typically in families that have BRCA mutations, cancer is more aggressive:

More than one person has been diagnosed with breast or ovarian cancer

Family members are diagnosed at younger ages

Family members may have been diagnosed with cancer in both breasts

There may be men in the family diagnosed with breast cancer

Up to 64% of breast cancer survivors who carry a BRCA mutation develop a second primary breast cancer and up to 50 % may develop ovarian cancer.

For survivors with a BRCA mutation, the chance of developing a recurrence in the same breast is also increased.

- ❖ Genetic testing is available to learn if you have a BRCA mutation.
- ❖ Genetic testing involves a blood test.
- ❖ It is important to undergo genetic counseling with a certified counselor before and after testing.

What about Black survivors and breast cancer genetics?

It is unknown if BRCA mutations are more common or less common among Black people compared to other racial and ethnic groups.

It is known that the chance of a unclear result following BRCA testing is higher among Black people.

An unclear result means that a mutation was found but its effect on breast cancer is not known.

There are no formal screening guidelines for breast cancer survivors with a BRCA mutation.

Some organizations recommend the same follow-up care and screening as other survivors plus

- ❖ pelvic exam 1-2 times a year
- ❖ vaginal ultrasound 1-2 times a year
- ❖ annual serum screening for CA-125, a tumor marker for ovarian cancer

Survivors with a BRCA mutation may also have surgery that removes the breasts or ovaries to help prevent cancer

Follow-up care and screening among breast cancer survivors

Studies have found that a surprising number of breast cancer survivors do not get adequate follow-up care after treatment, regardless of their racial or ethnic background.

Black survivors were half as likely to have a mammogram than White survivors in one study.

Also, the length of follow-up care for Black survivors was significantly shorter than that of White survivors in another study.

What keeps Black survivors from getting follow-up care?

- ❖ Lack of knowledge about the recommended guidelines for follow-up care
- ❖ Not asking one's doctor the right questions about follow-up care
- ❖ Fear of being diagnosed with cancer again
- ❖ Avoiding talk or thoughts about cancer because that experience is "over"
- ❖ Lack of support from family and friends
- ❖ Costs of medical care
- ❖ Lack of awareness of programs that can help with the costs of care

What motivates Black survivors to get follow-up care?

- ❖ Concerns about being diagnosed again
- ❖ Doctors' recommendations, support, care and concern
- ❖ Support from one's family
- ❖ Desire to survive to spend time with children and grandchildren
- ❖ Relationships with other breast cancer survivors
- ❖ Spiritual faith: Many survivors believe that even if a problem is found during follow up care, God will give them strength to handle it.
- ❖ Desire to live a healthy life

Take care of yourself!

- ❖ Be active in managing your stress
 - ❖ Research does not yet show a consistent link between stress and breast cancer.
 - ❖ However, we know that stress can affect your immune system and help cause illness so be mindful of stress in your life.

Take care of yourself!

The American Cancer Society has diet and exercise guidelines for cancer prevention:

- ❖ Eat a variety of healthy foods, especially fruits and vegetables
- ❖ Lead a physically active lifestyle
- ❖ Maintain a healthy weight
- ❖ Limit alcoholic drinks
- ❖ Be aware of food safety

During and after breast cancer treatment, a survivor's immune system may be weakened so be careful about eating certain foods, such as eggs, shellfish, food from salad bars, etcetera.

Teaching Breast Self-Examination (BSE)

When it comes to breast self-examination, survivors may face some special issues

- ❖ Some survivors may not feel comfortable looking at their breasts or touching their breasts after cancer treatment
- ❖ Also, after treatment, it may take a survivor some time to figure out what is now normal for her own breasts
- ❖ Surgery, radiation therapy and chemotherapy can change the firmness and color of the breast
- ❖ There may be small, hard bumps underneath or near incisions that are considered normal
- ❖ If the breast has been removed, ribs will be much closer to surface of the skin so don't confuse this with lumps
- ❖ Breasts may often be tender

During BSE, a woman is looking for any change in the breast

- ❖ Lumps
- ❖ Swelling
- ❖ Dimpling or puckering
- ❖ Changes in color of skin (redness or veins become visible)
- ❖ Nipple discharge
- ❖ Rashes
- ❖ Inverted nipples

Appendix C



Factors Influencing Post-Treatment Breast Cancer Surveillance among African-American and African-Caribbean Breast Cancer Survivors: A Qualitative Approach

Hayley Thompson, PhD, Monique Littles, MA,
Sherly Jacob, BS, & Crystal Coker, B.S.

Ruttenberg Cancer Center
Mount Sinai School of Medicine
New York, NY



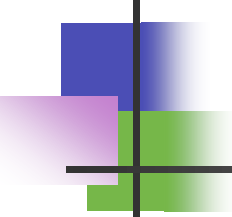
Introduction

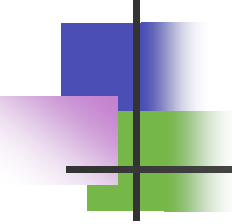
- Women diagnosed with breast cancer are at elevated risk of breast cancer recurrence as well as a second primary breast cancer.
- Breast cancer survivors represent a high-risk population for whom careful breast cancer surveillance is a priority.



The American Society of Clinical Oncology (ASCO) guidelines of breast cancer surveillance following primary treatment of breast cancer

- annual mammography
- monthly breast self-exam (BSE)
- regular pelvic exam and pap test
- physical examination every 3-6 months for the first 3 years, then every 6-12 months for the next 2 years, then annually
- symptom history every 3-6 months for the first three years after primary treatment, then every 6-12 months for the next 2 years, then annually.

- 
-
- A review of recent studies revealed that 22-45% of breast cancer reported no post-treatment mammogram during intervals ranging from 2-4 years.
 - In at least one study, African-American survivors approximately half as likely to have a mammogram compared to White survivors ⁸.
 - It has also been reported that duration of medical follow-up for Black survivors was significantly shorter than that of White survivors (53 vs. 65 months) ³⁵.

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-
- There are currently no data addressing factors that may account for ethnic disparities in breast cancer surveillance
 - The current study attempted to address the gap in the literature on breast cancer surveillance and follow-up care experiences of Black breast cancer survivors post-treatment.



Study Aims

- Key informant interviews were conducted with breast cancer survivors of African descent in order to explore the following:
 - recommendations received about follow-up care once their primary treatment ended
 - the follow-up care received in the past year
 - factors that are either motivators of or barriers to care
 - general attitudes and feelings about follow-up care.

Methods



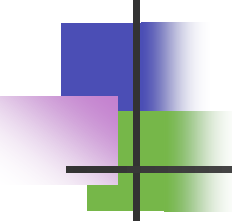
Participants

- 10 African-American and African-Caribbean breast cancer survivors who completed primary treatment for breast cancer at least one year before study participation.
- Primarily recruited from patient support groups and volunteer pools of cancer education and outreach programs.
- All participants had received a single breast cancer diagnosis with no recurrence or diagnosis of a second primary breast cancer.



Interview and Measures

- Sociodemographic variables (age, ethnicity, education level)
- Breast cancer history and treatment
- Table 1 summarizes participants' sociodemographic information as well as information about their breast cancer treatment and follow-up care.
- Open-ended interview questions were developed to address research questions (see Table 2).

- 
-
- Participants were also asked three closed-ended items :
 - I get enough information about breast cancer recurrence (getting breast cancer again) at my follow-up visits.
 - My emotional and psychological concerns are addressed at my follow-up visits.
 - I feel reassured by my follow-up visits.



Procedures and Analysis

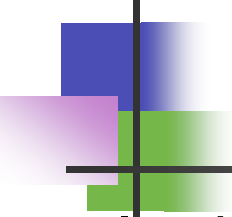
- Interviews were conducted either over the telephone or in person.
- All interviews were audio-taped and took between 30 and 60 minutes.
- An open-coding strategy was used to identify common concepts across participant responses and develop response categories.

Results



Participation in follow-up care

- All participants except one reported that they were provided with specific recommendations about follow-up care after primary treatment ended.
- None reported that they were given information that was completely consistent with all the ASCO recommendations.
- The most common recommendation reported was to increase the number physician visits over the course of a year.

- 
-
- In this sample, the mean number of physician visits in the past year was 6 (sd=3.5, range: 2-15 visits).
 - Specialties of physicians providing follow-up care is presented in Table 1.
 - The frequency of different breast cancer surveillance tests are presented in Table 2.
 - Only half of participants were adherent to ASCO guidelines for physical examination.

Factors influencing participation in follow-up care



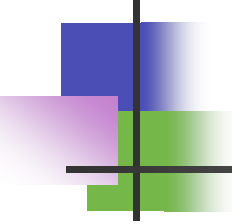
Desire to maintain good health

- The desire to either stay healthy, live a healthy life or, to live was most often cited first as a motivating factor in obtaining post-treatment follow-up care. Follow-up care was often associated with early breast cancer detection, which was widely viewed as a key component of staying healthy.
- *"I'm a firm believer that through early detection, you're going to alleviate a lot of problems. So, I think that continuous care is needed so in case there is a problem developing, we could, you know, address it early."*



Concerns and fears about recurrence

- Concern, worry, and fear about breast cancer recurrence were cited as motivating factors in obtaining follow-up care to the extent these feelings fostered vigilance about one's health.
- *"I'm concerned that the breast cancer might come back. But that will make me go more to get the care. But at the same time, you know, I try to be mindful that it's not a journey that I would not want to go on again because the second time around is definitely going to be worse than the first time. So, you know, I do try to do what's necessary, in order to avoid that experience again."*

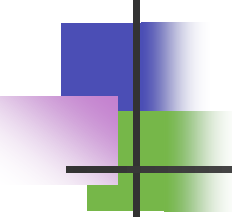
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-
- Concern and worry were also cited as potential barriers to care, especially the fear of being diagnosed again. Some participants suggested that some survivors may blunt their concerns and fears by deciding that the breast cancer experience is “over” and of little relevance to one’s life post-treatment. Toward this end, a survivor may avoid discussions about breast cancer and avoid those who were involved in her cancer care.

- *"I think also some people do want it to be over and you can bring some sort of finality to it if you are not seeing the same people as you did before."*



Support from health care providers

- Physician recommendation care was often endorsed as a motivator of participation in follow-up care. Interestingly, this was often not distinguished from personalized encouragement from physicians and participants' perceptions that their physicians genuinely cared about them as individuals.
 - *"...to be honest, my doctor, his concern motivated me. He cares so much, I need to care...he showed that he cared so much."*

- 
-
- Nurses and health educators were also members of participants' care teams and, in some cases, provided information and support that was not received from a physician.
 - *"I know about the regular check-ups. What I wasn't aware of is that a lot of it would be recommended, to get a lung x-ray once a year and also that it would be recommended to see a nutritionist but in talking to the clinical trial nurse and having some kind of ongoing dialogue with her, I was able to ask her what were her recommendations. I felt that, um, I could have gotten that information from my doctor, but I didn't. But I was still able to get it."*



Familial relationships

- Participants reported that they received both emotional and instrumental support from family members that encouraged them to obtain post-treatment follow-up care. Participants more often reported their strong connection to family as a motivating factor, especially the desire to have a long life in order to spend more time with one's children and grandchildren.
 - *"My family, I can't even express. My children, my husband, my sister, they have all been there for me. What motivated me more to continue my check-up is because I have grandchildren. I would kind of like to see them grow up. So I am very much, motivated myself in just to make to give the proper care."*



Lack of support from family and friends

- A number of participants also reported mixed support from family and friends post-breast cancer treatment. A common theme was that others were uncomfortable with or unaccepting of the participant's breast cancer experience. In other instances, family and friends had different views of the controllability of breast cancer that informed their opinions about follow-up care.
- *"My friends, well, it's a mixed thing. Some said nothing is wrong with me so I must not go and take the follow-up help. And some said go... because I, though I am a Christian, God said help those who help themselves. Yeah, so one side is telling me because I am a Christian I can't sick. You know some people? And one side is telling me that because I am a Christian, I must do what I have to do."*



Relationships with other survivors

- Interactions with other survivors were reported as motivation to participate in follow-up care in two ways. First, the support received from other survivors was often reported as helpful. Second, it was sometimes important for participants to serve as role models for other survivors.
 - *"I also educate women on breast health and I feel that I owe it to them. I have to follow up and take care of myself, so that my family and every one around me could see that it means something, you know. What I am saying is real and ,you know, I have to set an example."*



Lack of information about post-treatment follow-up care

- Participants frequently discussed lack of knowledge about the recommended follow-up care. It was suggested that low knowledge was, in part, a function of patient-provider interactions in which survivors do not ask their physicians appropriate questions about care or are unassertive in obtaining this information.
- *"Some people like to get information incrementally, on a need-to-know basis. And some doctors operate that you don't need to know and people accept that and I think that is a factor as well. In terms of if you don't really know what you need to be doing or what you should be doing and you don't ask the right questions."*



Medical care costs and access to care

- The cost of medical care was often cited as a reason why Black survivors may not be obtaining recommended follow-up care.
- *"A lot of women don't go to the doctor because they don't have the money or that don't have the insurance. But even if you don't have the insurance and you don't have any money, you can still go. They always have some sort of program that would pay for it. It's better to know, it's better to know if you have a condition that's there: the earlier, the better. That's my advice to them. Some of them don't go because they don't have the money to pay for it. I've heard that."*



Closed-ended items

-
- 1) I get enough information about breast cancer recurrence (getting breast cancer again) at my follow-up visits (70% agreed), 2) My emotional and psychological concerns are addressed at my follow-up visits (70% agreed), and 3) I feel reassured by my follow-up visits (80% agreed)



Discussion

Appendix D

Survivors in Spirit



**Looking Ahead to
Life After Breast Cancer Treatment**



What is *Survivors in Spirit*?

- ❖ *Survivors in Spirit (SIS)* is an educational program focusing on Black breast cancer survivors and the follow-up care that is recommended after they have completed primary treatment for breast cancer.



What is *Survivors in Spirit*?

- ❖ *S/S* is part of a research study funded by the Department of Defense Breast Cancer Research Program.
- ❖ The purpose of the study is to develop and test *S/S* as a way to increase follow-up care among Black breast cancer survivors.



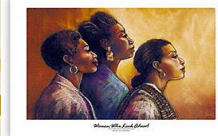
Why was *SIS* developed?

- ❖ Breast cancer survivors are at risk for recurrence (having the cancer reappear).
- ❖ A breast cancer survivor is 3 times as likely to develop a new breast cancer compared to a woman who has never had breast cancer.



Why was *SIS* developed?

- ❖ Once breast cancer treatment has ended, regular follow-up care and screening is important
- ❖ Regular follow-up care can detect a breast cancer recurrence or a new breast cancer at an early stage.
- ❖ Cancer found early is better treated and controlled.



Why does SIS focus on Black survivors?

- ❖ It has been reported that Black survivors
 - ❖ are half as likely to get a mammogram compared to White survivors.
 - ❖ are medically followed for a shorter period of time compared to White survivors.



What are the goals of *SIS*?

1. To increase awareness about the guidelines for follow-up care after breast cancer treatment among Black survivors.
2. To increase participation in follow-up care among Black survivors.



What are the guiding principles of *SIS*?

- ❖ Black survivors will be more likely to participate in follow-up care
 - ❖ if they hear from other Black survivors
 - ❖ if they feel supported by other Black women
 - ❖ if they have positive attitudes about that care



What are the guiding principles of *SIS*?

- ❖ Black survivors will be more likely to participate in follow-up care
 - ❖ if they are confident they can obtain that care
 - ❖ if they are presented with information that is specific to Black survivors



What are the guiding principles of *SIS*?

- ❖ Black survivors will be more likely to participate in follow-up care
 - ❖ If spirituality and faith is emphasized along with the information they receive
- ❖ Spirituality and faith is often an important part of the cultures of people of African descent
- ❖ Black and Latina survivors use more religious coping methods compared to White survivors



Who is part of *SIS*?

- ❖ Survivor speakers (breast cancer survivors) who
 - ❖ Share their stories of cancer diagnosis, treatment, follow-up care and well-being after treatment.
 - ❖ Express the role of spirituality and faith in their cancer experience
 - ❖ Serve as role models for other survivors



Who is part of *SIS*?

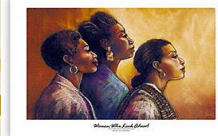
- ❖ Lay health educators who
 - ❖ Teach the facts about breast cancer recurrence
 - ❖ Inform survivors about the recommendations for follow-up care
 - ❖ Teach breast self-examination (BSE) to survivors
 - ❖ Provide information about breast health resources



Who is part of *SIS*?

❖ Staff members who

- ❖ Train survivor speakers and lay health educators to conduct *S/S* programs
- ❖ Coordinate *S/S* programs and identify survivors who would like to attend programs
- ❖ Interview these survivors before and after the *S/S* program to determine the impact the program had on them



The role of volunteers and staff is to:

- ❖ Educate

- ❖ Awareness guides action

- ❖ Encourage

- ❖ Be positive



The role of volunteers and staff is to:

- ❖ Present facts, not opinions
 - ❖ You may risk the project's reputation by stating opinions instead of facts
 - ❖ If you are not sure about something, be willing to say so and seek out the best answer



How does *SIS* work?

- ❖ Black survivors in the community are identified through physicians and other health care providers.
- ❖ These survivors are contacted by *S/S* staff and asked if they are interested in being in the research study that is testing the impact of *S/S*.
- ❖ If they are interested, these survivors are given a specific date, time, and place to attend a *S/S* program.



How does *SIS* work?

- ❖ Trained survivor speakers and lay health educators conduct the *S/S* program at that time and place.
- ❖ Because *S/S* is part of a research study, each survivor speaker and lay health educator will be offered \$25 for each program she conducts.
- ❖ We expect to conduct approximately 15 *S/S* programs over a 3-year period.



Good news about breast cancer survivors



- ❖ There are over 2 million female breast cancer survivors in the U.S.
- ❖ About 160,000 of these survivors are African American or Black.



Good news about breast cancer survivors

- ❖ Most women diagnosed with breast cancer survive and do not die of the disease.
- ❖ However, breast cancer survivors are at higher risk for breast cancer compared to other women never diagnosed.



What is a breast cancer recurrence?

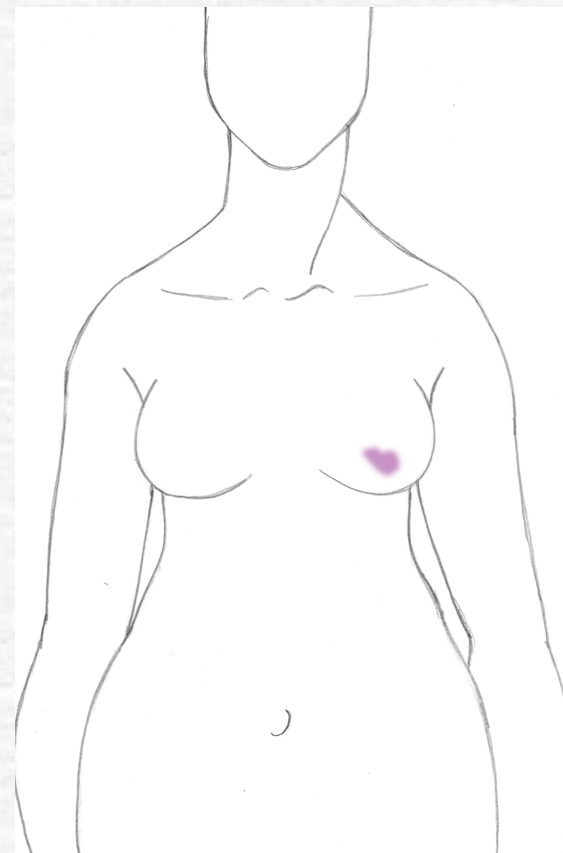
- ❖ The reappearance of a cancer that was thought to be cured or in remission, developed from cancer cells that were not destroyed by initial cancer treatment.
- ❖ Not all recurrences are the same.



Types of recurrence

❖ **Local recurrence:**

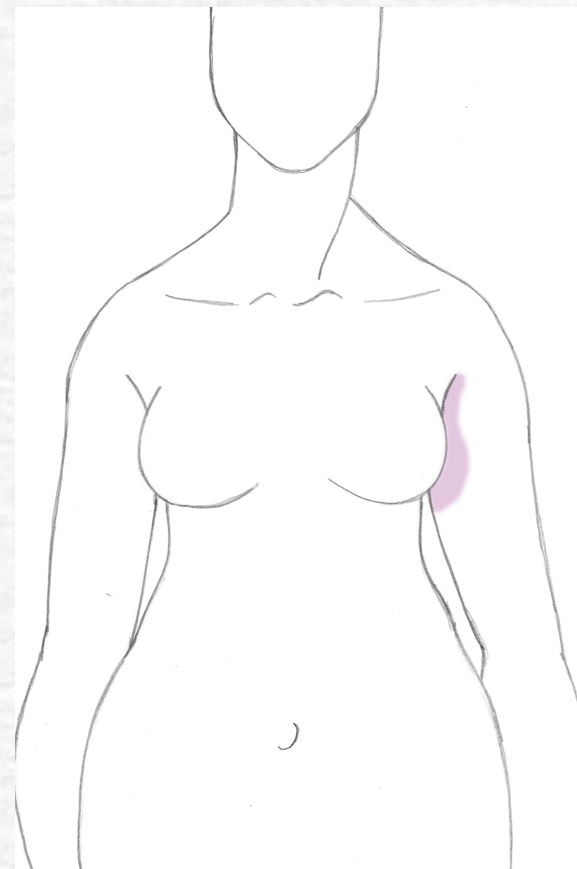
Recurrence found in the treated breast after breast-conserving treatment (such as lumpectomy) or the scar or chest wall after mastectomy





Types of recurrence

- ❖ **Regional recurrence:**
 - ❖ Recurrence found in nearby lymph nodes or other tissues
 - ❖ May occur in axillary lymph nodes (in armpits) and/or lymph nodes in the center of the chest and elsewhere near the chest.

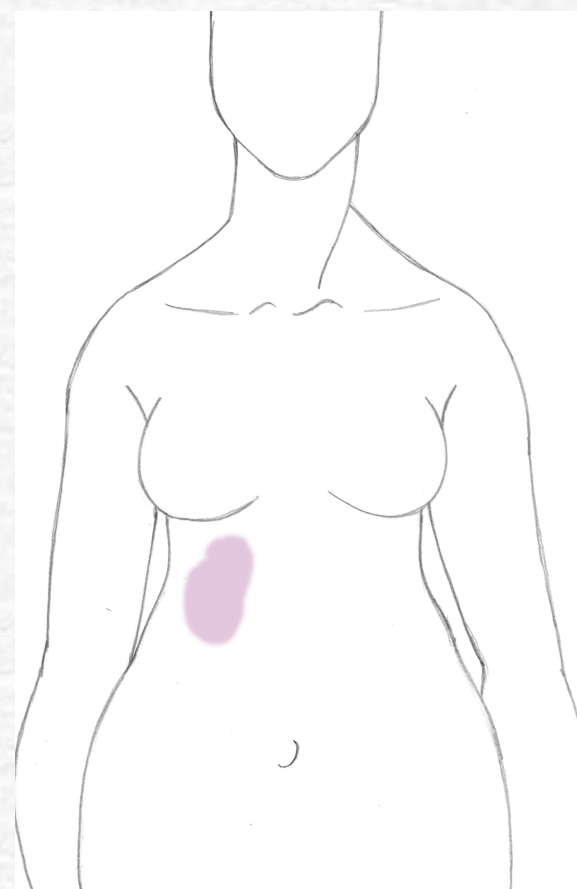




Types of recurrence

❖ **Distant recurrence:**

Recurrence in which the cancer has spread (metastasized) to organs or other tissues far from the breast where it was originally found, such as liver or lungs.





Types of recurrence

- ❖ Even if cancer reappears in a part of the body other than the breast, it is considered a breast cancer recurrence because it will usually have the same type of cells as the original tumor.



How common is recurrence?

- ❖ In large research studies focusing on survivors diagnosed with in situ, stage 1 or stage 2 disease
 - ❖ 5-10% of survivors had a local recurrence at 5-year follow-up.
 - ❖ 10-15% had a local recurrence at 10-year follow-up.



How common is recurrence?

- ❖ About 20% of survivors had a distant recurrence at 5-year follow-up.
- ❖ Between 20-35 % of survivors had a distant recurrence at 10-year follow-up.
- ❖ Regional recurrence alone is less common and can occur along with local or distant recurrence.



How common is recurrence?

- ❖ Approximately 70% of recurrences are identified within the first 5 years after diagnosis and treatment.
- ❖ Careful follow-up care and screening during this 5-year period is essential.



Does recurrence affect breast cancer survival?

- ❖ Survival at 5-year follow-up
 - ❖ Local recurrence: 72%
 - ❖ No recurrence: 87%

- ❖ A woman can still be a long-term survivor after a local recurrence



Black survivors and recurrence

- ❖ Black breast cancer survivors may have less favorable recurrences.
- ❖ More involvement of the skin
- ❖ It is not clear whether rates of recurrence among Black survivors are higher than other groups or similar.





Risk factors for breast cancer recurrence

- ❖ A survivor has little control over most of the risk factors for recurrence.
- ❖ However, awareness of risk factors may encourage a woman to work more closely with her doctors in getting follow-up care.



Risk factors for breast cancer recurrence: Age

- ❖ Younger survivors are at greater risk for breast cancer recurrence
 - ❖ “Young” means anywhere from 35-50 years in most studies.
 - ❖ Younger women have a longer life expectancy and more time for cancer to recur.



Risk factors for breast cancer recurrence: Age

- ❖ There is a relationship between menopause (change of life), hormones and cancer growth.
- ❖ Younger women may have more unfavorable cancers.



Risk factors for breast cancer recurrence: Features of the tumor

- ❖ Information about one's tumor is in a pathology report that is part of one's medical records.
- ❖ Several features are believed to be strong risk factors

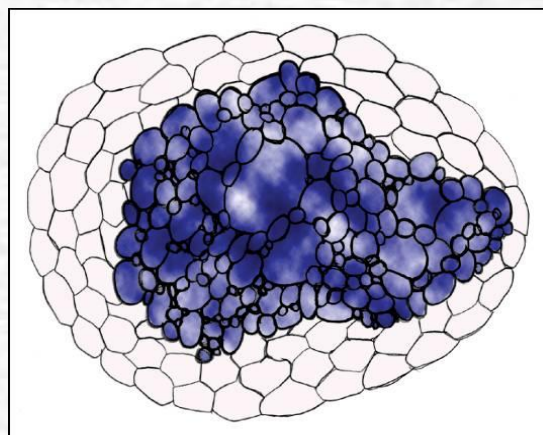


Risk factors for breast cancer recurrence: Features of the tumor

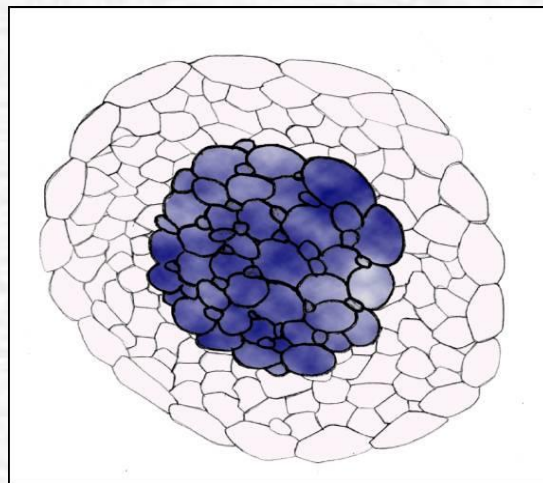
- ❖ Positive/close and unclear or unknown resection margins:

If cancer is found at the edge of tumor tissue removed during surgery (or if it is unclear or unknown if cancer is at the edge), the risk of recurrence is greater.

Positive margins



Negative margins





Risk factors for breast cancer recurrence: Features of the tumor

- ❖ Extent of intraductal cancer (cancer in breast ducts):

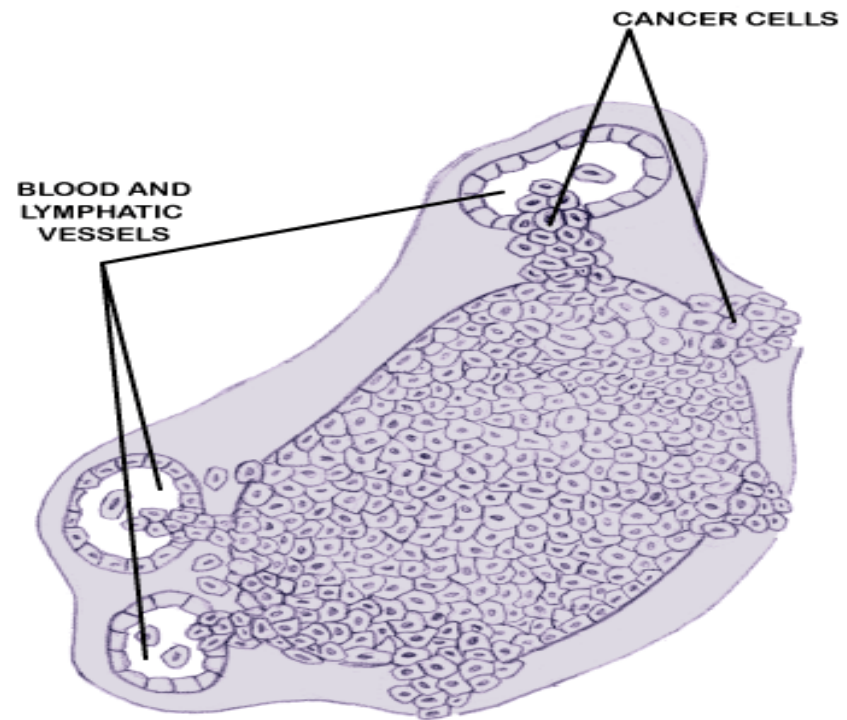
The more cancer found in the ducts surrounding the tumor, the higher the risk of recurrence.



Risk factors for breast cancer recurrence: Features of the tumor

❖ Vascular invasion (cancer in blood/lymphatic vessels):

The more that cancer cells have entered the vessels surrounding the tumor, the greater the risk of recurrence.





Risk factors for breast cancer recurrence: Features of the tumor

- ❖ Positive lymph nodes
 - ❖ The more lymph nodes that are determined to be positive (be cancerous), the greater the chance of recurrence



Regular follow-up care and screening for breast cancer recurrence

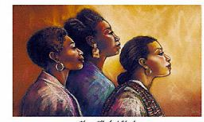


- ❖ Regular follow-up care and screening leads to early detection.
- ❖ There are benefits to early detection.
- ❖ Getting regular follow-up care and screening can detect a tumor at an earlier stage and when it is smaller



Regular follow-up care and screening for breast cancer recurrence

- ❖ When a survivor detects a recurrence or second primary at an early stage, she is more likely to recover.
- ❖ Breast cancer found early is
 - ❖ more treatable
 - ❖ better controlled



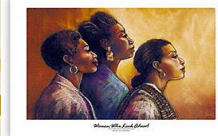
Regular Follow-up Care and Screening for Breast Cancer Recurrence

- ❖ Finding the cancer early may extend a survivor's life (survival) and improve her quality of life.



Regular follow-up care and screening for breast cancer recurrence

- ❖ Survivors who find a recurrence when the tumor is smaller and less invasive are less likely diagnosed with a distant recurrence later on in life.



American Society of Clinical Oncologists (ASCO) Guidelines for Follow-up Care and Screening after Breast Cancer Treatment



- ❖ A full physical examination and symptom history
 - ❖ 2-4 times a year for the first 3 years (4-6 months)
 - ❖ 1-2 times for the next 2 years (6-12 months)
 - ❖ Once a year after that
- ❖ Annual mammogram (with first one performed 6 months after the end of treatment)
- ❖ Monthly breast self-exam (BSE)
- ❖ Regular pelvic exam and pap test



ASCO Guidelines: Full physical exam and symptom history

- ❖ Approximately 70% of recurrences are detected by patients themselves based on symptoms they notice between routine visits
- ❖ Physical exam can detect a recurrence even if the survivor has no symptoms



ASCO Guidelines: Symptoms of Recurrence

- ❖ Any changes in the breast
 - ❖ mass or skin rash

- ❖ Symptoms of bone metastasis (most common)
 - ❖ bone pain or tenderness

- ❖ Symptoms of pulmonary (lung) metastasis
 - ❖ Chest pain or difficulty breathing



ASCO Guidelines: Symptoms of Recurrence

- ❖ Gynecologic symptoms
 - ❖ vaginal discharge or spotting or abdominal pain

- ❖ Central nervous system (CNS) symptoms
 - ❖ seizures, persistent headache, changes in mental functioning, problems with movement, or sensory loss (problems seeing, hearing, etc.)



ASCO Guidelines: Symptoms of Recurrence

- ❖ Symptoms of liver metastasis
 - ❖ Discomfort, fullness or pain in the right upper part of body, fullness or pain, weight loss

- ❖ Other general symptoms including fatigue



ASCO Guidelines: Symptoms of Recurrence

- ❖ If a survivor notices suspicious or persistent symptoms, she should talk with her doctor as soon as possible.



ASCO Guidelines: Annual Mammogram

- ❖ Six months after treatment, a baseline mammogram should be performed once changes due to surgery and radiation have stabilized
- ❖ After that, a mammogram should be conducted at least once a year
- ❖ A doctor may order more mammograms based on findings



ASCO Guidelines: Annual Mammogram

- ❖ Regular mammograms detect breast cancer recurrence and second primaries when tumors are smaller and at an earlier stage.



ASCO Guidelines: Monthly Breast Self-Exam

- ❖ Should be performed on both breasts, even if the survivor has had a mastectomy or has a prosthesis.
- ❖ In survivors who have had a mastectomy, local recurrence may occur in the chest wall and skin flaps.



ASCO Guidelines: Regular Pelvic Exam & Pap Test

- ❖ A vaginal/rectal examination and pap test is recommended due to the increased risk of endometrial cancer (cancer in the uterus), especially in women taking tamoxifen
- ❖ symptoms include vaginal discharge and bleeding or spotting
- ❖ Women who have had a hysterectomy should consult with their physician as they may be examined less frequently.



ASCO Guidelines

- ❖ Studies have compared these guidelines to more extensive testing, such as blood tests, bone scans, CT scans, and MRIs.
- ❖ There is no difference between the ASCO guidelines and more extensive testing terms of
 - ❖ Time to recurrence detection
 - ❖ Mortality
 - ❖ Survival



ASCO Guidelines

- ❖ The ASCO guidelines represent the minimum follow-up care that a survivor should receive.
- ❖ A survivor may choose to have more extensive follow-up if she and her doctor decide that is best.



Second primary breast cancer

- ❖ If a survivor is diagnosed with cancer in the breast that was not originally affected (the opposite breast), this is referred to as
 - ❖ a second primary breast cancer
 - ❖ a new primary
 - ❖ contralateral breast cancer



Second primary breast cancer

- ❖ This is a new cancer that is unrelated to the first and is not a recurrence.
- ❖ 2-11% of survivors may develop a second primary.
- ❖ Chemotherapy and tamoxifen can lower your risk of a developing a second primary



Risk factors for a second primary breast cancer

- ❖ Younger age
- ❖ Family history of breast cancer
 - ❖ specifically mother or sister diagnosed with breast cancer
 - ❖ Not the same as genetic risk for breast cancer



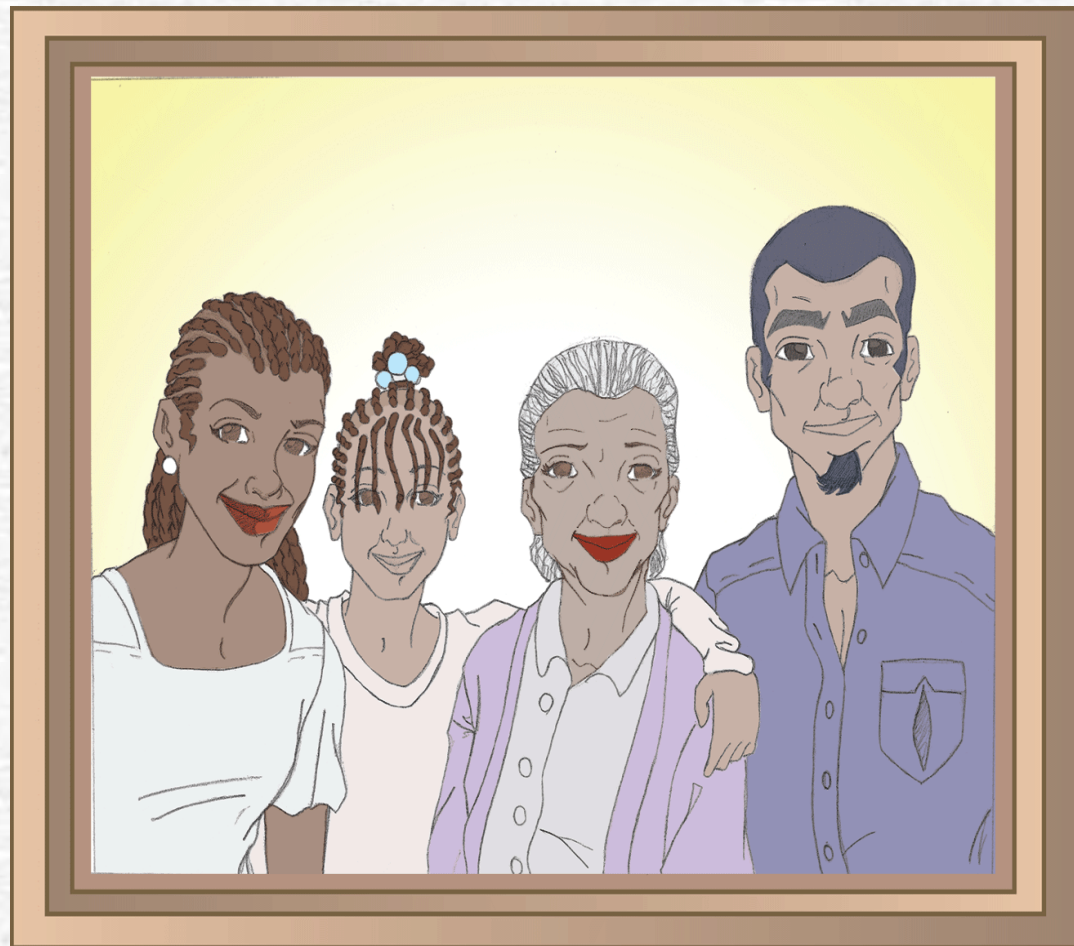
Breast cancer genetics

- ❖ Genes are in every cell of our bodies and control different functions.
- ❖ Genes called BRCA1 and BRCA2 control breast cell growth.
- ❖ Mutations or changes in these genes increase the risk of breast and ovarian cancer.



Breast cancer genetics

- ❖ BRCA mutations occur in about 10% of breast cancer survivors and their families.
- ❖ Breast cancer is “passed down” through generations.





Breast cancer genetics

Typically in these families:

- ❖ More than one person has been diagnosed with breast or ovarian cancer
- ❖ Family members are diagnosed at younger ages
- ❖ Family members may have been diagnosed with cancer in both breasts
- ❖ There may be men in the family diagnosed with breast cancer



Breast cancer genetics

- ❖ Up to 64% of breast cancer survivors who carry a BRCA mutation develop a second primary breast cancer.
- ❖ A survivor's chance of developing a recurrence in the same breast is also increased.
- ❖ For a survivor who has a BRCA mutation, the risk of developing ovarian cancer is up to 50%.



Genetic counseling and testing

- ❖ Genetic testing is available to learn if you have a BRCA mutation.
- ❖ Genetic testing involves a blood test.
- ❖ It is important to undergo genetic counseling with a certified counselor before and after testing.



Black survivors and breast cancer genetics

- ❖ It is unknown if BRCA mutations are more common or less common among Black people compared to other racial/ethnic groups.
- ❖ It is known that the chance of an ambiguous or unclear result following BRCA testing is higher among Black people.
 - ❖ A mutation may be found but its effect on breast cancer is not known.



There are no formal screening guidelines for breast cancer survivors with a BRCA mutation.

- ❖ Some organizations recommend the same follow-up care and screening as other survivors plus
 - ❖ Pelvic exam 1-2 times a year
 - ❖ Transvaginal ultrasound (with color Doppler) 1-2 times a year



- ❖ Annual serum screening for CA-125, a tumor marker for ovarian cancer
- ❖ Option of prophylactic mastectomy and prophylactic oophorectomy
 - ❖ Removing the breasts and/or ovaries for cancer prevention



Follow-up care and screening among breast cancer survivors

- ❖ Studies suggest that a surprising number of breast cancer survivors do not get adequate follow-up care after treatment, regardless of racial/ethnic background.



Follow-up care and screening among breast cancer survivors

- ❖ Survivors most likely to get a mammogram were those who were
 - ❖ treated at a comprehensive breast center
 - ❖ treated with radiation
 - ❖ employed
 - ❖ more than 6 years from diagnosis
 - ❖ originally diagnosed through a mammogram
 - ❖ lacking a recommendation from their doctor to have a mammogram



Black survivors and follow-up care

- ❖ Black survivors were half as likely to have a mammogram than White survivors in one study.
- ❖ The length of follow-up care for Black survivors was significantly shorter than that of White survivors (53 vs. 65 months) in another study.



What keeps Black survivors from getting follow-up care?

- ❖ Lack of knowledge about the recommended guidelines for follow-up care.
- ❖ Not asking one's doctor the right questions about follow-up care.
- ❖ Fear of being diagnosed with cancer again.
- ❖ Avoiding talk or thoughts about cancer because that experience is "over."



What keeps Black survivors from getting follow-up care?

- ❖ Lack of support from family and friends.
- ❖ Costs of medical care.
- ❖ Lack of awareness of programs that can help with the costs of care.



What motivates Black survivors to get follow-up care?

- ❖ Concerns about being diagnosed again
- ❖ Doctors' recommendations, support, care and concern
- ❖ Support from one's family



What motivates Black survivors to get follow-up care?

- ❖ Desire to survive to spend time with children and grandchildren
- ❖ Relationships with other breast cancer survivors
- ❖ Desire to live a healthy life



Take care of yourself!

- ❖ Be active in managing your stress
 - ❖ Research does not yet shown a consistent link between stress and breast cancer.
 - ❖ However, we know that stress can affect your immune system and help cause illness.



Take care of yourself!

- ❖ The American Cancer Society has diet and exercise guidelines for cancer prevention
 - ❖ Eat a variety of healthful foods, especially fruits and vegetables
 - ❖ Lead a physically active lifestyle
 - ❖ Maintain a healthy weight
 - ❖ Limit consumption of alcoholic beverages
 - ❖ Be aware of food safety



Teaching Breast Self-Examination (BSE)

- ❖ Special issues for breast cancer survivors
 - ❖ Some survivors may not feel comfortable looking at their breasts or touching their breasts after cancer treatment
 - ❖ Surgery, radiation therapy and chemotherapy can change the firmness and color of the breast



Teaching Breast Self-Examination (BSE)

- ❖ Special issues for breast cancer survivors
 - ❖ There may be small, hard bumps underneath or near incisions that are normal
 - ❖ If the breast has been removed, ribs will be much closer to surface of the skin
 - ❖ Breasts may often be tender



Teaching Breast Self-Examination (BSE)

- ❖ During BSE, a woman is looking for any change in the breast
 - ❖ Lumps
 - ❖ Swelling
 - ❖ Dimpling
 - ❖ Changes in color of skin (redness or veins become visible)
 - ❖ Nipple discharge
 - ❖ Rashes



What is the format of a *SIS* program?

1. Program is opened with prayer or words of devotion or inspiration.
2. Introduce the program and the goals of the program.
3. Show *S/S* video?
4. Testimonies of at least 2 survivor speakers.



5. Lay health educators discuss recurrence facts, risk factors, follow-up care guidelines, and recurrence symptoms.
6. Survivor speakers discuss reasons why survivors may or may not get care and present resources.
7. All *S/S* presenters teach and demonstrate BSE.
8. Program is closed with prayer or words of devotion or inspiration.

Appendix E

Time 1 – Part 1

(Baseline Assessment)

- Section 1. Sociodemographics/Medical History/Physician Specialty and Background
- Section 2. Mammography Adherence, Attitudes, Norms, Intention & Behavioral Control
- Section 3. Physical Examination Adherence, Attitudes, Norms, Intention & Behavioral Control
- Section 4. Symptom History Adherence, Intention, and Behavioral Control
- Section 5. BSE Adherence, Intention, and Behavioral Control
- Section 6. Pelvic Exam/Pap Test Adherence, Intention, and Behavioral Control
- Section 7. Other Follow-up Tests and Care
- Section 8. Surveillance Behavioral Beliefs
- Section 9. Surveillance Social Influence/Normative Beliefs
- Section 10. Breast Cancer Recurrence/Surveillance Knowledge
- Section 11. Perceived Breast Cancer Recurrence Risk
- Section 12. Ethnic Identity
- Section 13. Impact of Events Scale
- Section 14. Perceived Access to Healthcare
- Section 15. Genetic Testing Awareness and Interest

SIS caller/recruiter

SIS interviewer

Date

Time of interview start

Time of interview end

Last updated 11/01/05, 12:48 PM (HT)

Section 1.

Social Demographics/Medical History/ Physician Specialty and Background

1. What is your date of birth? ____/____/____ What is your age? _____ years of age
2. Are you
 - ☐ Currently married
 - ☐ Currently living with partner
 - ☐ Separated
 - ☐ Divorced
 - ☐ Widowed
 - ☐ Never married
- 3a. Do you have any children? ☐ Yes ☐ No If yes, how many? _____
- 3b. Do you have any daughters age 18 or older? ☐ Yes ☐ No If yes, how many? _____
4. Are you currently employed? ☐ Yes ☐ No
5. What is the highest level of education that you completed?
 - ☐ Less than 8th grade
 - ☐ 8th to 11th grades
 - ☐ High School graduate
 - ☐ Some college or university
 - ☐ Vocational or technical school
 - ☐ Bachelor's Degree
 - ☐ Graduate Degree
6. What is the estimated total income for your household for the past year, before taxes, from all sources?
 - ☐ Less than \$10,000
 - ☐ \$10,000 to \$19,999
 - ☐ \$20,000 to \$39,999
 - ☐ \$40,000 to \$59,999
 - ☐ \$60,000 to \$100,000
 - ☐ More than \$100,000
7. How many people are supported by this income? _____
8. Which of the following best describes you? Choose as many that apply.
 - ☐ Black-American/African American
 - ☐ Afro-Caribbean/West Indian
 - Which ethnic group (i.e. Jamaican, Guyanese)? _____
 - ☐ African
 - Which ethnic group (i.e. Igbo, Yoruba)? _____
 - ☐ Afro-Latina
 - Which group (i.e., Puerto Rican, Dominican)? _____
 - ☐ Other _____
9. In which country were you born?
(Please indicate which state if born in US.) _____

10. How many years have you lived in the US? _____ years _____ months

11. Do you live continuously in the US (at least 8 months out of the year)? ☐ Yes ☐ No

12. Which religion do you identify with, if any?

- ☐ Catholic
☐ Protestant (i.e. Lutheran, Baptist, Methodist)
☐ Jewish
☐ Muslim
☐ Hindu
☐ Buddhist
☐ None
☐ Don't know
☐ Other: please specify _____

13. What type of health insurance do you have? Choose as many that apply.

- ☐ Medicaid
☐ Medicare
☐ Employer-provided insurance (like Oxford, Blue Cross/Blue Shield, HIP)
☐ Pay for insurance out-of-pocket
☐ I do not have health insurance (pay out of pocket for health care)
☐ Other _____
☐ Don't know

Interviewer: Complete this section based on intake sheet and Project 1 database and check accuracy with participant.

13. When were you first diagnosed with breast cancer (month/year): _____

14. Breast cancer diagnosed in one or both breasts? ☐ One ☐ Both

15. What type of treatment did you receive for your breast cancer?

a. Mastectomy (total removal of the breast) ☐ Yes ☐ No Date of surgery _____

b. Breast conserving surgery (partial removal of the breast) ☐ Yes ☐ No Date of surgery _____

c. Radiation therapy ☐ Yes ☐ No When did radiation end? _____

d. Chemotherapy ☐ Yes ☐ No When did chemotherapy end? _____

e. Hormonal therapy (Tamoxifen, etc.) ☐ Yes ☐ No When did hormonal therapy end? _____

16a. Were you diagnosed with breast cancer again after the first diagnosis? ☐ Yes ☐ No

16b. Were you diagnosed with any other type of cancer after the first breast cancer diagnosis? ☐ Yes ☐ No

17. What type of doctor do you see for follow-up care since you have completed your breast cancer treatment?

You may indicate more than one type of doctor.

- ☐ Surgeon (doctor who performed surgery on your breast to treat the cancer)
- ☐ Male ☐ Female Estimated ethnicity/race _____
- ☐ Radiation oncologist (doctor who specializes in radiation to treat breast cancer)
- ☐ Male ☐ Female Estimated ethnicity/race _____
- ☐ Medical oncologist (doctor who uses chemotherapy, hormone therapy and other medications to treat cancer)
- ☐ Male ☐ Female Estimated ethnicity/race _____
- ☐ Primary care physician (doctor who is trained to give you basic care. This is often a family physician or internist.)
- ☐ Male ☐ Female Estimated ethnicity/race _____
- ☐ Gynecologist (doctor who specializes in treating diseases of the female reproductive organs, or the parts of the body related to having sex and having a baby)
- ☐ Male ☐ Female Estimated ethnicity/race _____
- ☐ Other _____
- ☐ Male ☐ Female Estimated ethnicity/race _____

18. How much do you agree with the following statement?

“Overall, I am satisfied with my follow-up care I have received since completing breast cancer treatment.”

- ☐ Strongly Agree
- ☐ Agree
- ☐ Not Sure/ Undecided
- ☐ Disagree
- ☐ Strongly Disagree

19. Have you had any relatives or family members who have had cancer?

☐ Yes ☐ No

Please list any relatives or family members who have had cancer. If a family member had more than one type of cancer, please list them twice. If a family member had breast cancer, please indicate whether one or both breasts were affected.

<i>Family Member (e.g. grandmother, aunt)</i>	<i>Paternal or Maternal</i>	<i>Type or Location of Cancer (e.g. breast, prostate)</i>	<i>Age at Diagnosis</i>	<i>Did this person die from this cancer?</i>
	<input type="checkbox"/> P <input type="checkbox"/> M			<input type="checkbox"/> Yes <input type="checkbox"/> No
	<input type="checkbox"/> P <input type="checkbox"/> M			<input type="checkbox"/> Yes <input type="checkbox"/> No
	<input type="checkbox"/> P <input type="checkbox"/> M			<input type="checkbox"/> Yes <input type="checkbox"/> No
	<input type="checkbox"/> P <input type="checkbox"/> M			<input type="checkbox"/> Yes <input type="checkbox"/> No
	<input type="checkbox"/> P <input type="checkbox"/> M			<input type="checkbox"/> Yes <input type="checkbox"/> No
	<input type="checkbox"/> P <input type="checkbox"/> M			<input type="checkbox"/> Yes <input type="checkbox"/> No

20. Have you ever had any of the following medical conditions?

(Check one box on each line)

a. Diabetes	<input type="checkbox"/> Yes	<input type="checkbox"/> No
b. Heart attack, chest pain	<input type="checkbox"/> Yes	<input type="checkbox"/> No
c. Stroke	<input type="checkbox"/> Yes	<input type="checkbox"/> No
d. Amputation	<input type="checkbox"/> Yes	<input type="checkbox"/> No
e. Circulation problems in your legs or feet	<input type="checkbox"/> Yes	<input type="checkbox"/> No
f. Asthma, emphysema, breathing problems	<input type="checkbox"/> Yes	<input type="checkbox"/> No
g. Stomach ulcer, irritable bowel	<input type="checkbox"/> Yes	<input type="checkbox"/> No
h. Kidney disease	<input type="checkbox"/> Yes	<input type="checkbox"/> No
i. Major depression	<input type="checkbox"/> Yes	<input type="checkbox"/> No
j. Seizures	<input type="checkbox"/> Yes	<input type="checkbox"/> No
k. Alcoholism or alcohol problems	<input type="checkbox"/> Yes	<input type="checkbox"/> No
l. Drug Problems	<input type="checkbox"/> Yes	<input type="checkbox"/> No
m. Current or past cigarette smoker	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Section 2

Mammography Adherence, Attitudes, Norms, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____

REMIND THE PARTICIPANT OF THE DATE SHE ENDED TREATMENT!!!!

1. Since you completed breast cancer treatment, has your doctor recommended that you have mammogram?

☐ Yes ☐ No ☐ Not sure

2. Since you completed breast cancer treatment, have you had a mammogram?

☐ Yes ☐ No ☐ Not sure

3. Since you completed breast cancer treatment, how many mammograms have you had in total?

☐ None ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

4. Were any of these mammograms not routine (you had it because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

5. How many mammograms have you had in the past 12 months?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

6a. When was the date of your last mammogram? Date _____

a ☐ Within the past 6 months

b ☐ Between 7 – 12 months ago

c ☐ Between 13 – 18 months ago

d ☐ Between 19 – 24 months ago

e ☐ More than 24 months ago

f ☐ Not sure

Interviewer:

Participant is adherent if she chooses a or b. Go to Section 2A on page 6.

Participant is non-adherent if she chooses c, d, e or f. Go to Section 2B on page 7.

6b. When was the date of the mammogram before the one in 6a? Date _____

☐ 6 months before

☐ Between 7 – 12 months before

☐ Between 13– 18 months before

☐ Between 19 – 24 months before

☐ More than 24 months before

☐ Not sure

7. Do you have an appointment to have a mammogram?

☐ I have an appointment When? _____

☐ I have tried to make an appointment recently but I do not have one

☐ I have no appointment

Section 2A

Interviewer: If participant has had a mammogram in the past year (ADHERENT) based on 6a, ask all of the questions on this page!!!!

8a. How much do you agree or disagree with this statement: "I intend to have a mammogram at least 12 months from the date of my last mammogram."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

9a. How much control do you have over getting a mammogram at least 12 months from the date of your last mammogram?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

10a. Having a mammogram at least 12 months from the date of your last mammogram will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

11a. Please tell me how much you agree or disagree with the following statements. Do you think that having a mammogram at least 12 months from the date of your last mammogram would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

12a. Most people who are important to you think you should have a mammogram at least 12 months from your last one.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 2B

Interviewer: If participant has not had a mammogram in the past year (NOT ADHERENT) based on 6a, ask all of the questions on this page!!!

8b. How much do you agree or disagree with this statement: "I intend to have a mammogram sometime in the next 12 months."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

9b. How much control do you have over getting a mammogram sometime in the next 12 months?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

10b. Having a mammogram sometime in the next 12 months will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

11b. Please tell me how much you agree or disagree with the following statements. Do you think that getting a mammogram in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

12b. Most people who are important to you think you should have a mammogram sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3

Physical Examination Adherence, Attitudes, Norms, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____

REMINDE THE PARTICIPANT OF THE DATE SHE ENDED TREATMENT!!!!

1. Since you completed breast cancer treatment, has your doctor recommended that you have a physical examination (physical examination is an evaluation of the body and its functions using inspection, feeling with the hands, tapping with the fingers, and listening)?

☐ Yes ☐ No ☐ Not sure

2. Since you completed breast cancer treatment, have you had a physical examination?

☐ Yes ☐ No ☐ Not sure

3. What type of doctor have you seen for a physical examination? **You may indicate more than one type of doctor.**

☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Since you completed breast cancer treatment, how many physical examinations have you had in total ?

☐ None ☐ 1-3 ☐ 4-6 ☐ 7-9 ☐ 10 or more

5. Were any of these examinations not routine (you went because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

6. How many physical examinations have you had in the past 12 months?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

7. When was the date of your last physical examination? Date _____

a ☐ Within the past 3 months
b ☐ Between 4- 6 months ago
c ☐ Between 7 – 12 months ago
d ☐ More than 12 months ago
e ☐ Not sure

Interviewer:

If participant is 3 years or fewer post-treatment, she is adherent if she chooses a or b (go to Section 3A on page 10) and non-adherent if she chooses c, d or e (go to Section 3B on page 11).

If participant is more than 3 years post-treatment, she is adherent if she chooses a, b, or c (go to Section 3C on page 12) and non-adherent if she chooses d or e (go to Section 3D on page 13).

8. Do you have an appointment to have a physical examination?

- ☐ I have an appointment When? _____
- ☐ I have tried to make an appointment recently but I do not have one
- ☐ I have no appointment

Section 3A

Interviewer: If it has been 3 years or less since completion of treatment AND participant had an exam at least 6 months ago (ADHERENT) ask all of the questions on this page.

9a. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 6 months from the date of my last exam."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

10a. How much control do you have over having a physical examination at least 6 months from the date of your last exam?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11a. Having a physical examination at least 6 months from the date of your last exam will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12a. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 6 months from the date of your last exam would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13a. Most people who are important to you think you should have a physical examination at least 6 months from the date of your last exam.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3B

Interviewer: If it has been 3 years or less since completion of treatment AND it has been more than 6 months since exam (NOT ADHERENT) ask all of the questions on this page.

9b. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 6 months."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

10b. How much control do you have over having a physical examination sometime in the next 6 months?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11b. Having a physical examination sometime in the next 6 months will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12b. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination in sometime the next 6 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13b. Most people who are important to you think you should have a physical examination sometime in the next 6 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3C

Interviewer: If it has been more than 3 years since completion of treatment AND participant had an exam at least 12 months ago (ADHERENT) ask all of the questions on this page.

9c. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 12 months from the date of my last exam."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

10c. How much control do you have over having a physical examination at least 12 months from the date of your last one?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11c. Having a physical examination at least 12 months from the date of your last one will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- Very difficult*

12c. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 12 months from the date of your last one would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13c. Most people who are important to you think you should have a physical examination at least 12 months from the date of your last one.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3D

Interviewer: If it has been more than 3 years since completion of treatment AND it has been more than 12 months since exam. (NOT ADHERENT) ask all of the questions on this page.

9d. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 12 months."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

10d. How much control do you have over having a physical examination sometime in the next 12 months?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11d. Having a physical examination sometime in the next 12 months will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12d. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13d. Most people who are important to you think you should have a physical examination sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 4

Symptom History Adherence, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____
REMIND THE PARTICIPANT OF THE DATE SHE ENDED TREATMENT!!!!

To be read by interviewer: I am now going to ask you some questions about how often you have talked with a doctor about breast cancer symptoms or problems since you have completed breast cancer treatment. I realize that these discussions often take place during physical exams but some survivors have these discussions in between exams.

1. Since you completed breast cancer treatment, has any doctor recommended that you talk about your symptoms or problems related to breast cancer?

☐ Yes ☐ No ☐ Not sure

2. Since you completed breast cancer treatment, has a doctor asked you about any symptoms or problems related to breast cancer?

☐ Yes ☐ No ☐ Not sure

3. What type of doctor asked you about symptoms or problems related to breast cancer? **You may indicate more than one type of doctor.**

- ☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Since you completed breast cancer treatment, how many times has a doctor asked you about symptoms or problems related to breast cancer, in total ?

☐ None ☐ 1-3 ☐ 4-6 ☐ 7-9 ☐ 10 or more

5. Were any of these discussions not routine (you had the discussion because you had specific symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

6. How many times has a doctor asked you about symptoms or problems related to breast cancer in the past 12 months?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

7. When was the date of your last discussion of symptoms? Date _____

- a ☐ Within the past 3 months
b ☐ Between 4 - 6 months ago
c ☐ Between 7– 12 months ago
d ☐ More than 12 months ago
e ☐ Not sure

Interviewer:

If participant is 3 years or fewer post-treatment, she is adherent if she chooses a or b (go to Section 4A on page 16) non-adherent if she chooses c, d or e (go to Section 4B on page 17).

If participant more than 3 years post-treatment, she is adherent if she chooses a, b, or c (go to Section 4C on page 18) and non-adherent if she chooses d or e (go to Section 4D on page 19).

8. Do you have an appointment to discuss any symptoms or problems?

- ☐ I have an appointment When? _____
- ☐ I have tried to make an appointment recently but I do not have one
- ☐ I have no appointment

Section 4A

Interviewer: If it has been 3 years or less since completion of treatment AND participant had a symptom history at least 6 months ago. (ADHERENT) ask all of the questions on this page!!!

9a. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 6 months from the last time I did so."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

10a. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11a. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12a. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 4B

Interviewer: If it has been 3 years or less since completion of treatment AND it has been more than 6 months since symptom history (NOT ADHERENT) ask all of the questions on this page!!!

9b. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 6 months who will ask me about any symptoms or problems related to breast cancer."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

10b. How much control do you have over going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11b. Going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12b. Most people who are important to you think you should go to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 4C

Interviewer: If it has been more than 3 years since the completion of treatment AND participant had a symptom history at least 12 months ago (ADHERENT) ask all of the questions on this page!!!

9c. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 12 months from the last time I did so."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

10c. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11c. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12c. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 4D

Interviewer: If it has been more than 3 years since completion of treatment AND it has been more than 12 months since symptom history. (NOT ADHERENT) ask all of the questions on this page!!!

9d. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 12 months who will ask me about any symptoms or problems related to breast cancer."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

10d. How much control do you have over going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

11d. Going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

12d. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 5
BSE Adherence, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____
REMIND THE PARTICIPANT OF THE DATE SHE ENDED TREATMENT!!!!

1. Do you know how to do a breast self-exam (check your own breasts)?

☐ Yes ☐ No ☐ Not sure

2. How confident are you that you are able to do a breast self-exam correctly?

☐ Very confident
☐ Fairly confident
☐ A little confident
☐ Not at all confident

3. Since you completed your treatment for breast cancer, has your doctor ever recommended that you do a breast self-exam

☐ Yes ☐ No ☐ Not sure

4. Since you completed breast cancer treatment, have you done a breast self-exam?

☐ Yes ☐ No ☐ Not sure

5. How many breast self exams have you done in the past 12 months?

☐ None ☐ 1-4 ☐ 5-9 ☐ 10-12 ☐ 13 or more

6. When was your last breast self-exam? Date _____

☐ Within the past week
☐ Within the past month
☐ Within the past 2-3 months
☐ Within the past 4-6 months
☐ Within the 7-12 months
☐ More than 12 months ago
☐ Not sure

7. How often do you perform breast self-examination (BSE)?

☐ Never
☐ At least once a day
☐ Once a week
☐ Twice a month
☐ Once a month
☐ Once every other month (six times a year)
☐ Two or three times a year
☐ Once a year
☐ When I have symptoms or problems

8. How much do you agree or disagree with this statement: "I intend to do breast self exam every month?"

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

9. How much control do you have doing breast self-exam every month?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

10. Doing breast self-exam every month would be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

11. Most people who are important to you think you should do a breast self-exam every month.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 6
Pelvic Exam/Pap Test Adherence, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____
REMIND THE PARTICIPANT OF THE DATE SHE ENDED TREATMENT!!!!

1. Since you completed breast cancer treatment, has your doctor ever recommended that you have a pelvic exam and pap test?

☐ Yes ☐ No ☐ Not sure

2. Since you completed breast cancer treatment, have you had a pelvic exam and pap test?

☐ Yes ☐ No ☐ Not sure

3. Since you completed breast cancer treatment, how many pelvic exams/pap tests have you had in total?

☐ None ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

4. Were any of these pelvic exams/pap tests not routine (you had it because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

5. How many pelvic exams/pap tests have you had in the past 12 months?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

6. When was your last pelvic exam/pap test? Date _____

- a ☐ Within the past 6 months
- b ☐ Within the past 7-12 months
- c ☐ Within the past 13-24 months years
- d ☐ More than 24 months ago
- e ☐ Not sure

Interviewer:

Participant is adherent if she chooses a or b. Go to Section 6A on page 23.

Participant is non-adherent if she chooses c, d or e. Go to Section 6B on page 24.

7. Do you have an appointment to have a pelvic exam and pap test?

- ☐ I have an appointment When? _____
- ☐ I have tried to make an appointment recently but I do not have one
- ☐ I have no appointment

Section 6A

Interviewer: If participant has had a pelvic exam/ pap test in the past year (ADHERENT) ask all of the questions on this page!!!

8a. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test 12 months from the date of my last pelvic exam/pap test."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

9a. How much control do you have over having a pelvic exam and pap test 12 months from the date of your last one?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

10a. Having a pelvic exam and pap test 12 months from the date of your last one will be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

11c. Most people who are important to you think you should have a pelvic exam and pap test 12 months from the date of your last one.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 6B

Interviewer: If participant has not had a pelvic exam/ pap test in the past year (NOT ADHERENT) ask all of the questions on this page!!!

8b. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test sometime in the next 12 months."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

9b. How much control do you have over having a pelvic exam and pap test sometime in the next 12 months?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

10b. Getting your next pelvic exam and pap test sometime in the next 12 months will be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

11b. Most people who are important to you think you should have a pelvic exam and pap test sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 7

Other Follow-up Tests & Care

Interviewer: REMIND THE PARTICIPANT OF THE DATE SHE ENDED TREATMENT!!!!

1. Since completing breast cancer treatment, have you had other types of follow-up tests? **Select all that apply.**

☐ CT scan or CAT scan (Computed tomography scan: A computerized x-ray procedure that produces cross-sectional images of the body.

☐ Ultrasound (also known as a sonogram, this technique uses sound waves to make pictures of the body organs and obtain images for medical diagnosis

☐ MRI (Magnetic resonance imaging: A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.

☐ X-rays (electromagnetic radiation used to produce images of bones, organs, and internal tissues)

☐ Blood tests

☐ Bone scans (A technique to create images of bones on a computer screen or on film after an injection of a small amount of radioactive material)

☐ Biopsies on either of your breasts. (The removal of tissues from the living body for testing to help make a medical diagnosis)

☐ Other _____

2. Since completing breast cancer treatment

a. Have you made any changes to your diet? ☐ Yes ☐ No

b. Have you decreased the amount of fat in your diet? ☐ Yes ☐ No

c. Have you increased the amount of fiber in your diet? ☐ Yes ☐ No

d. Have you decreased the amount of red meat in your diet? ☐ Yes ☐ No

e. Have you increased your use of vitamins and dietary supplements? ☐ Yes ☐ No

f. Have you increased your use of herbal remedies? ☐ Yes ☐ No

g. Have you started exercising more? ☐ Yes ☐ No

h. Have you increased the amount of fruits and vegetables in your diet? ☐ Yes ☐ No

Section 8
Breast Cancer Surveillance Behavioral and Control Beliefs

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

The first set of questions asks about the follow-up care you may be receiving since you have completed breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
1.	I would probably not have follow-up care unless I had some breast symptoms or discomfort.	1	2	3	4	5
2.	Those people who are close to me will benefit if I have regular breast cancer follow-up care.	1	2	3	4	5
3.	If follow-up care finds a problem, whatever is there will probably be too far along to do anything about it anyway.	1	2	3	4	5
4.	I would be more likely to have regular follow-up care if my doctor told me how important it is.	1	2	3	4	5
5.	Regular follow-up care is too expensive for me.	1	2	3	4	5
6.	I don't have time for regular follow-up care.	1	2	3	4	5
7.	Regular follow-up care gives me a feeling of control over my health.	1	2	3	4	5
8.	If I eat a healthy diet, I will lower my risk of getting breast cancer far enough that I probably do not need regular follow-up care.	1	2	3	4	5
9.	Regular follow-up care gives me peace of mind over my health.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
10.	I would probably not have regular follow-up care if my doctor seemed to doubt I really needed it.	1	2	3	4	5
11.	Regular follow-up care causes me unnecessary worry.	1	2	3	4	5
12.	I am afraid to have regular follow-up care because I might find out something is wrong.	1	2	3	4	5

The next set of questions refer to feelings about follow-up care after breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
13.	I would be ashamed if follow-up care found that I have breast cancer again.	1	2	3	4	5
14.	Other people would view me negatively if follow-up care found that I had breast cancer again.	1	2	3	4	5
15.	I would be angry if follow-up care found that I had breast cancer again.	1	2	3	4	5
16.	I would be frightened if follow-up care found that I had breast cancer again.	1	2	3	4	5
17.	I would not be able to handle it emotionally if follow-up care found that I had breast cancer again.	1	2	3	4	5
18.	I would feel a sense of hopelessness and despair if follow-up care found that I had breast cancer again.	1	2	3	4	5

The next set of questions refer to mammograms and breast self-exams.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
19.	Having a mammogram is painful.	1	2	3	4	5
20.	Having a mammogram is embarrassing.	1	2	3	4	5
21.	If I receive a clinical breast exam from a doctor or nurse, I don't need to have a mammogram.	1	2	3	4	5
22.	If I do breast self-exam (check my own breasts), I don't need to have a mammogram.	1	2	3	4	5
23.	The results of mammograms are not trustworthy.	1	2	3	4	5
24.	Having a mammogram exposes me to unnecessary radiation.	1	2	3	4	5
25.	I am uncomfortable doing breast self-exam (checking my own breasts) because since I was treated for cancer, I'm not sure if what I'm feeling during the exam is normal or not.	1	2	3	4	5
26.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to look at my breasts since being treated for cancer.	1	2	3	4	5
27.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to touch my breasts since being treated for cancer.	1	2	3	4	5

Section 9
Social Influence/Normative Beliefs

Think about how much you agree or disagree with each of the following statements about follow-up care after breast cancer treatment. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly Disagree	Moderately Disagree	Undecided / Not sure	Moderately Agree	Strongly Agree
1.	I have talked to or heard from breast cancer survivors who have regular follow-up care.	1	2	3	4	5
2.	I have talked to or heard from breast cancer survivors who benefit from regular follow-up care.	1	2	3	4	5
3.	I have received information about regular follow-up care that is useful to me as a Black survivor.	1	2	3	4	5
4.	I have received trustworthy information about regular follow-up care.	1	2	3	4	5
5.	I have talked to or heard from friends think I should have regular follow-up care.	1	2	3	4	5
6.	I have talked to or heard from my spouse or partner who thinks I should have regular follow-up care. <i>Not applicable</i>	1	2	3	4	5
7.	I have talked to or heard from family members who think I should have regular follow-up care.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided/ Not sure	Moderately agree	Strongly agree
8.	I have talked to or heard from people in my church or house of worship who think I should have regular follow-up care. <i>Not applicable</i>	1	2	3	4	5
9.	I have talked to or heard from my doctors or other healthcare providers who think I should have regular follow-up care.	1	2	3	4	5
10.	I have talked to or heard from other breast cancer survivors think I should have regular follow-up care.					
11.	I have talked to or heard from other Black women think I should have regular follow-up care.	1	2	3	4	5
12.	Most people who are important to me think I should have regular follow-up care.	1	2	3	4	5

Section 10
Breast Cancer Surveillance Knowledge Questionnaire

Please answer the following questions True, False, or Not sure.

1.	Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
2.	Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
3.	Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
4.	Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
5.	Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
6.	Breast cancer survivors only need to have physical exams about once a year after they have completed breast cancer treatment.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
7.	Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
8.	Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
9.	Women diagnosed with breast cancer need to examine their own breasts every day.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
10.	Chest pain and problems with breathing can be signs of breast cancer recurrence.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure

Section 11

Perceived Breast Cancer Recurrence Risk

1. On a scale of 0 to 100 where 0 means “no chance” and 100 means “guaranteed to happen,” how would you rate your chances of getting breast cancer again? _____
2. What do you think your chances are of being diagnosed with breast cancer again?
 - ☐ Very low
 - ☐ Low
 - ☐ Average
 - ☐ High
 - ☐ Very high
 - ☐ Not sure
3. On a scale of 0 to 100 where 0 means “not bad at all” and 100 means “the worst possible situation”, how bad would it be if you were to get breast cancer again? _____
4. On a scale of 0% to 100%, what percentage of all breast cancer survivors do you think will get breast cancer again? _____
5. Compared to other women who have had breast cancer, what do you think your chances are of being diagnosed with breast cancer again?
 - ☐ I am at much less risk than others
 - ☐ I am at somewhat less risk than others
 - ☐ My risk is about the same as others
 - ☐ I am at somewhat higher risk than others
 - ☐ I am at much higher risk than others
 - ☐ Not sure
6. How worried are you about getting breast cancer again?
 - ☐ Extremely worried
 - ☐ Moderately worried
 - ☐ Undecided/not sure
 - ☐ A little worried
 - ☐ Not at all worried
7. What do you think your chances are of getting a new cancer of some other type?
 - ☐ I am at much less risk than others
 - ☐ I am at somewhat less risk than others
 - ☐ My risk is about the same as others
 - ☐ I am at somewhat higher risk than others
 - ☐ I am at much higher risk than others
 - ☐ Not sure
8. How worried are you about getting a new cancer of some other type?
 - ☐ Extremely worried
 - ☐ Moderately worried
 - ☐ Undecided/not sure
 - ☐ A little worried
 - ☐ Not at all worried

9. What do you think your chances are of developing heart disease (high blood pressure, stroke, heart attack, etc.)?

- ☐ I am at much less risk than others
- ☐ I am at somewhat less risk than others
- ☐ My risk is about the same as others
- ☐ I am at somewhat higher risk than others
- ☐ I am at much higher risk than others
- ☐ Not sure
- ☐ I have already been diagnosed with heart disease

10. How worried are you about developing heart disease?

- ☐ Extremely worried
- ☐ Moderately worried
- ☐ Undecided/not sure
- ☐ A little worried
- ☐ Not at all worried
- ☐ I have already been diagnosed with heart disease

Section 12
Multidimensional Inventory of Black Identity (Centrality subscale)

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2= Disagree
3=Agree
4=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly disagree	Disagree	Agree	Strongly agree
1.	Overall, being Black has very little to do with how I feel about myself	1	2	3	4
2.	In general, being Black is an important part of my self-image	1	2	3	4
3.	My destiny is tied to the destiny of other Black people.	1	2	3	4
4.	Being Black is unimportant to my sense of what kind of person I am	1	2	3	4
5.	I have a strong sense of belonging to Black people.	1	2	3	4
6.	I have a strong attachment to other Black people.	1	2	3	4
7.	Being Black is an important reflection of who I am.	1	2	3	4
8.	Being Black is not a major factor in my social relationships.	1	2	3	4

Section 13

Impact of Events Scale

I'm going to read you a list of comments made by people about stressful life events. Using the scale 0=not at all, 1= rarely, 3=sometimes, and 5=often, please indicate how frequently these comments were true for you about breast cancer DURING THE PAST WEEK, INCLUDING TODAY.

0=Not at all

1=Rarely

3=Sometimes

5=Often

		Not at all	Rarely	Sometimes	Often
1.	Thought about breast cancer when I didn't mean to.	0	1	3	5
2.	I avoided letting myself get upset when I thought about it or was reminded of breast cancer.	0	1	3	5
3.	I tried to remove breast cancer from memory.	0	1	3	5
4.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about breast cancer that came into my mind.	0	1	3	5
5.	I had waves of strong feelings about breast cancer.	0	1	3	5
6.	I stayed away from reminders about breast cancer.	0	1	3	5
7.	I had dreams about breast cancer.	0	1	3	5
8.	I felt as if breast cancer was unreal.	0	1	3	5
9.	I tried not to talk about breast cancer.	0	1	3	5
10.	Pictures about breast cancer popped into my mind.	0	1	3	5
11.	Other things kept making me think about breast cancer .	0	1	3	5
12.	I was aware that I had a lot of feelings about breast cancer but I didn't deal with them.	0	1	3	5
13.	I tried not to think about breast cancer .	0	1	3	5
14.	Any reminder brought back feelings about breast cancer.	0	1	3	5
15.	My feelings about breast cancer were kind of numb.	0	1	3	5

Section 14

Perceived Access to Health Services

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree

2= Disagree

3=Agree

4=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly disagree	Disagree	Agree	Strongly agree
1.	I am able to get medical care whenever I need it.	1	2	3	4
2.	Sometimes it is a problem to cover my share of the cost for a medical visit.	1	2	3	4
3.	Sometimes I go without the medical care I need because it is too expensive.	1	2	3	4
4.	Places where I can get medical care are conveniently located.	1	2	3	4
5.	If I have a medical question, I can reach a doctor or nurse for help.	1	2	3	4
6.	Health care providers often don't listen to people.	1	2	3	4
7.	I have easy access to the medical specialists I need.	1	2	3	4
8.	I don't worry much about the cost when I know I need to seek medical care.	1	2	3	4
9.	I see a different health care provider almost every time I go to an appointment.	1	2	3	4
10.	Money is an issue to me when I need to see the doctor.	1	2	3	4

Section 15

Genetic Testing Awareness and Interest

1. How much have you heard or read about genetic testing for breast cancer risk?

- ☐ Almost Nothing
☐ Relatively Little
☐ A Fair Amount
☐ A lot

2. At the present time, how interested are you in getting genetic testing for breast cancer risk?

- ☐ Not at all interested
☐ Slightly interested
☐ Moderately interested
☐ Very interested

3. Now that such a test is currently available, which of the following best describes your intentions?

- ☐ I have already donated a blood sample for genetic testing.
☐ I plan to take the test as soon as possible (within the next 30 days).
☐ I plan to take the test sometime in the near future (within the next 6 months).
☐ I do not plan to take the test in the near future (not within the next 6 months).
☐ I do not plan to take the test at all.

Is there anything else you would like to share with me related to breast cancer recurrence that I have not asked you about?

May we have your permission to contact you in the future about other research studies?

☐ Yes ☐ No

Time 1 - Part 2

(Baseline Assessment)

- Section 1. Spirituality
- Section 2. Group-Based Medical Mistrust/Trust in Physician
- Section 3. Participatory Decision Making
- Section 4. Concerns About Recurrence Scale

SIS caller/recruiter _____

SIS interviewer _____

Date _____

Time of interview start _____

Time of interview end _____

Last updated 4/7/05, 1:20 PM (HT)

Section 1 Spirituality

1. Are you a member of a church or other place of worship?

- ☐ Yes
☐ No

2. How often do you attend church or other religious services?

- ☐ More than once per week
☐ Once a week
☐ A few times a month
☐ A few times a year
☐ Once a year or less
☐ Never

3. How often do you spend time in private religious activities, such as prayer, meditation or Bible study?

- ☐ More than once per week
☐ Once a week
☐ A few times a month
☐ A few times a year
☐ Once a year or less
☐ Never

Please consider the following statements. Think about how true each one is for you and then indicate how strongly you agree or disagree with each one.

1. I talk openly about my faith with others.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
2. I often read religious books, magazines, or pamphlets.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
3. I often watch or listen to religious programs on television or radio	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
4. My spiritual beliefs are the foundation of my whole approach to life	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
5. I am often aware of the presence of God in my life.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
6. I have a personal relationship with God.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
7. When I am ill, I pray for healing.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree

8. I pray often.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
9. I rely on God to keep me in good health.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
10. If I lead a good spiritual life, I will stay healthy.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
11. If I stay healthy, it is because I am right with God	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
12. Through my faith in God, I can stay healthy.	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree

Section 32 Medical Mistrust

These questions ask about your beliefs about the care you and other people of your racial and ethnic group receive from doctors, nurses, and other staff people in the health care system. Please indicate how much you agree or disagree with the following statements.

Check one answer for each question.

1.	Doctors and health care workers sometimes hide information from patients who belong to my ethnic group.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
2.	Doctors have the best interests of people of my ethnic group in mind.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
3.	People of my ethnic group should not confide in doctors and health care workers because it will be used against them.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
4.	People of my ethnic group should be suspicious of information from doctors and health care workers.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
5.	People of my ethnic group cannot trust doctors and health care workers.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
6.	People of my ethnic group should be suspicious of modern medicine.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
7.	Doctors and health care workers treat people of my ethnic group like “guinea pigs”.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
8.	People of my ethnic group receive the same medical care from doctors and health care workers as people from other groups.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
9.	Doctors and health care workers do not take the medical complaints of people of my ethnic group seriously.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
10.	People of my ethnic group are treated the same as people of other groups by doctors and health care workers.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree

11.	In most hospitals, people of different ethnic groups receive the same kind of care.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
12.	I have personally been treated poorly or unfairly by doctors or health care workers because of my ethnicity.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree

Please check the one box on each line that best matches your answer. Please think about the doctor you see most often for your follow-up care since you have been completed breast cancer treatment.

Which doctor do you see most often for your follow-up care since you have been completed breast cancer treatment?

- ☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

1.	I doubt that my doctor really cares about me as a person.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
2.	My doctor is usually considerate of my needs and puts them first.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
3.	I trust my doctor so much I always try to follow his/her advice.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
4.	If my doctor tells me something is so, then it must be true.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
5.	I sometimes distrust my doctor's opinion and would like a second one.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
6.	I trust my doctor's judgments about my medical care.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
7.	I feel my doctor does not do everything he/she should for my medical care.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
8.	I trust my doctor to put my medical needs above all other considerations when treating my medical problems.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree

9.	My doctor is a real expert in taking care of medical problems like mine.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
10.	I trust my doctor to tell me if a mistake was made about my treatment.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree
11.	I sometimes worry that my doctor may not keep the information we discuss totally private.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly Disagree

Section 3 Participatory Decision Making

1. Which doctor do you see most often for your follow-up care since you have been completed breast cancer treatment?

- ☐ Surgeon
- ☐ Radiation oncologist
- ☐ Medical oncologist
- ☐ Primary care physician
- ☐ Gynecologist
- ☐ Other _____

2. Please check the box next to the statement that best matches the involvement you prefer to have in making decisions about the follow-up care you receive since you have finished breast cancer treatment.

Please think about the doctor you see most often for your follow-up care since you have been completed breast cancer treatment.

Only select one statement.

- ☐ I prefer to make the decisions about what care I will receive.
- ☐ I prefer to make the final decisions about my care after seriously considering my doctor's opinion.
- ☐ I prefer that my doctor and I share responsibility for deciding what care is best for me.
- ☐ I prefer that my doctor make the final decisions about what care will be used but seriously consider my opinion.
- ☐ I prefer to leave all decisions regarding care to my doctor.

3. Please check the box next to the statement that best matches the involvement you actually have in decisions about the follow-up care you have receive since finishing your breast cancer treatment.

Only select one statement.

- ☐ I make the decisions about the care I receive.
- ☐ I make the final decisions about my care after seriously considering my doctor's opinion.
- ☐ My doctor and I share responsibility for deciding what care is best for me.
- ☐ My doctor makes the final decisions about what care I receive but the doctor seriously considers my opinion.
- ☐ I leave the decisions regarding care to my doctor.

Section 4

Concerns About Breast Cancer Recurrence

DIRECTIONS: The following questions ask you to tell us about any worries you may have about the possibility of breast cancer recurrence. By recurrence we mean the breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast.

Although most women who have been diagnosed with early stage breast cancer will never have another problem with the cancer, we are aware that many women do worry about this possibility. Other women may not worry about recurrence at all. Either way, your answers to these questions are very important to us. We understand that it may be upsetting to think about or answer questions about the possibility of recurrence. However we need you help to understand how women think about this possibility.

For the following four questions please circle the number that comes closest to the way you feel. For example, for the first question you should circle “1” if you don’t think about recurrence at all, circle “6” if you think about recurrence all the time, or circle “2”, “3”, “4” or “5” if the amount of time you spend thinking about recurrence is somewhere in between.

1. How much time do you spend thinking about the possibility that your breast cancer could recur?

1 2 3 4 5 6

**I Don’t Think
About It At All**

**I Think About It
All The Time**

2. How much does the possibility that your breast cancer could recur upset you?

1 2 3 4 5 6

**It Does Not
at all**

**It Makes Me
Extremely Upset**

3. How often do you worry about the possibility that your breast cancer could recur?

1 2 3 4 5 6

**I Never Worry
About It**

**I Worry About
It All The Time**

4. How afraid are you that your breast cancer may recur?

1 2 3 4 5 6

Not At All Afraid

Very Afraid

Now we are interested in what your concerns are regarding a possible recurrence of breast cancer. When thinking about the possibility of recurrence what is it about that possibility that you worry about?

Although each of the following items may be possible consequence of recurrence, we are really interested in whether you actually worry about any of these things occurring. For example, you may believe that a recurrence of breast cancer could require further surgery. We would like to know whether you ever actually worry about this possibility.

For the following questions, please circle the number indicating how much you worry about each of the following items. If you do not worry about an item or if you think it does not apply to you, please check “Not at all.”

I worry that a recurrence of breast cancer would:

5.	Upset me emotionally	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
6.	Keep me from doing the things I had planned to do	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
7.	Threaten my physical health	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
8.	Make me feel I am less of a woman	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
9.	Require chemotherapy	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
10.	Hurt my relationships with friends and family	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
11.	Make me feel that I don't have control over my life	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
12.	Threaten my identity (how I see myself)	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
13.	Interfere with my physical ability to carry out daily activities	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
14.	Threaten life	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely

15.	Harm my self –confidence	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
16.	Be more serious than the first diagnosis	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
17.	Cause financial problems for me	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
18.	Interfere with my sense of sexuality	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
19.	Require radiation treatment	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
20.	Cause pain and suffering	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
21.	Mean losing my breast(s)	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
22.	Interfere with my ability to plan for the future	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
23.	Threaten my spirituality or faith	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
24.	Keep me from fulfilling important roles (in my job or at home)	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
25.	Lead me to feel less feminine	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
26.	Require further surgery	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
27.	Cause me to die	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
28.	Damage my romantic relationship(s)	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
29.	Keep me from fulfilling my responsibilities (in my job or at home)	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely
30.	Make me feel badly about how my body looks or feels	<input type="checkbox"/> Not at all	<input type="checkbox"/> A Little	<input type="checkbox"/> Moderately	<input type="checkbox"/> A lot	<input type="checkbox"/> Extremely

Time 2

(One-month follow-up assessment)

- Section 1. Mammography Adherence, Intention and Physician Recommendation
- Section 2. Physical Exam Adherence, Intention, and Behavioral Control
- Section 3. Symptom History Adherence, Intention, and Behavioral Control
- Section 4. BSE Adherence, Intention, and Behavioral Control
- Section 5. Pelvic Exam/Pap Test Adherence, Intention, and Behavioral Control
- Section 6. Other Follow-up Tests and Care
- Section 7. Breast Cancer Surveillance Attitudes
- Section 8. Social Influence/Norms
- Section 9. Breast Cancer Recurrence/Surveillance Knowledge
- Section 10. Perceived Breast Cancer Recurrence Risk
- Section 11. Genetic Testing Awareness and Interest

Date of Interview 1 _____

SIS interviewer _____

Date _____

Time of interview start _____

Time of interview end _____

Last updated 4/8/05, 1:20 PM (HT)

Section 1
Mammography Adherence, Intention & Behavioral Control

Interviewer: Was participant adherent to mammography in baseline interview? ☐ Yes ☐ No

1. Since the last interview, has your doctor recommended that you have mammogram?

☐ Yes ☐ No ☐ Not sure

2. Since the last interview, have you had a mammogram?

☐ Yes ☐ No ☐ Not sure

If yes, when? _____

3. If yes, was this mammogram not routine (you had it because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

4. Do you have an appointment to have a mammogram?

☐ I have an appointment When? _____

☐ I have tried to make an appointment since the last interview but I do not have one

☐ I have no appointment

Section 1A

Interviewer: If

a) **participant was adherent at baseline**

b) **OR participant has had a mammogram since baseline**

ask all of the questions on this page!!!!

5a. How much do you agree or disagree with this statement: "I intend to have a mammogram at least 12 months from the date of my last mammogram."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

6a. How much control do you have over getting a mammogram at least 12 months from the date of your last mammogram?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

7a. Having a mammogram at least 12 months from the date of your last mammogram will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

8a. Please tell me how much you agree or disagree with the following statements. Do you think that having a mammogram at least 12 months from the date of your last mammogram would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

9a. Most people who are important to you think you should have a mammogram at least 12 months from your last one.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 1B

Interviewer: If participant was not adherent at baseline AND has not had a mammogram since baseline, ask all of the questions on this page!!!

5b. How much do you agree or disagree with this statement: "I intend to have a mammogram sometime in the next 12 months."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

6b. How much control do you have over getting a mammogram sometime in the next 12 months?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

7b. Having a mammogram sometime in the next 12 months will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

8b. Please tell me how much you agree or disagree with the following statements. Do you think that getting a mammogram in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

9b. Most people who are important to you think you should have a mammogram sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 2
Physical Exam Adherence, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____

Interviewer: Was participant adherent to Physical Exam in baseline interview? ☐Yes ☐No

1. Since the last interview, has your doctor recommended that you have a physical examination (physical examination is an evaluation of the body and its functions using inspection, feeling with the hands, tapping with the fingers, and listening)?

☐Yes ☐No ☐Not sure

2. Since the last interview, have you had a physical examination?

☐Yes ☐No ☐Not sure

If yes, when? _____

3. If yes, what type of doctor did you see? **You may indicate more than one type of doctor.**

☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Was this exam not routine (you went because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

5. Do you have an appointment to have a physical examination?

☐I have an appointment When? _____
☐I have tried to make an appointment recently but I do not have one
☐I have no appointment

Section 2A

Interviewer: If

a) has been 3 years or less since completion of treatment,

b) participant was adherent at baseline

c) OR participant has had a physical exam since baseline

ask all of the questions on this page!!!!

6a. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 6 months from the date of my last exam."

- ☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

7a. How much control do you have over having a physical examination at least 6 months from the date of your last exam?

- ☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8a. Having a physical examination at least 6 months from the date of your last exam will be

- ☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9a. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 6 months from the date of your last exam would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10a. Most people who are important to you think you should have a physical examination at least 6 months from the date of your last exam.

- ☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2B

Interviewer: If
a) has been 3 years or less since completion of treatment,
b) participant was not adherent at baseline
c) AND has not had a physical exam since baseline
ask all of the questions on this page!!!!

6b. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 6 months."

- ☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

7b. How much control do you have over having a physical examination sometime in the next 6 months?

- ☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8b. Having a physical examination sometime in the next 6 months will be

- ☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9b. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 6 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10b. Most people who are important to you think you should have a physical examination in the next 6 months.

- ☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2C

Interviewer: If

a) has been more than 3 years since completion of treatment,

b) participant was adherent at baseline

c) OR participant has had a physical exam since baseline

ask all of the questions on this page!!!!

6c. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 12 months from the date of my last exam."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

7c. How much control do you have over having a physical examination at least 12 months from the date of your last one?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

8c. Having a physical examination at least 12 months from the date of your last one will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- Very difficult*

9c. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 12 months from the date of your last one would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10c. Most people who are important to you think you should have a physical examination at least 12 months from the date of your last one.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 2D

Interviewer: If
a) has more than 3 years since completion of treatment,
b) participant was not adherent at baseline
d) AND has not had a physical exam since baseline
ask all of the questions on this page!!!!

6d. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 12 months."

- ☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

7d. How much control do you have over having a physical examination sometime in the next 12 months?

- ☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8d. Having a physical examination sometime in the next 12 months will be

- ☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9d. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10d. Most people who are important to you think you should have a physical examination sometime in the next 12 months.

- ☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3 Symptom History Adherence, Intention & Behavioral Control

Interviewer: Time since completion of primary treatment _____

Interviewer: Was participant adherent to Symptom History in baseline interview? ☐Yes ☐No

To be read by interviewer: *I am now going to ask you some questions about how often you have talked with a doctor about breast cancer symptoms or problems since you have completed breast cancer treatment. I realize that these discussions often take place during physical exams but some survivors have these discussions in between exams.*

1. Since the last interview, has your doctor recommended that see a doctor who can ask you about symptoms or problems related to breast cancer?

☐Yes ☐No ☐Not sure

2. Since the last interview, has a doctor asked you about any symptoms or problems related to breast cancer?

☐Yes ☐No ☐Not sure

If yes, when? _____

3. If yes, what type of doctor asked you about symptoms or problems related to breast cancer? **You may indicate more than one type of doctor.**

- ☐ Surgeon
- ☐ Radiation oncologist
- ☐ Medical oncologist
- ☐ Primary care physician
- ☐ Gynecologist
- ☐ Other _____

4. Was this discussion not routine (you went because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

5. Do you have an appointment to discuss any symptoms or problems related to breast cancer?

- ☐I have an appointment When? _____
- ☐I have tried to make an appointment recently but I do not have one
- ☐I have no appointment

Section 3A

Interviewer: If

a) has been 3 years or less since completion of treatment,

b) participant was adherent at baseline

c) OR participant has done a symptom history since baseline

ask all of the questions on this page!!!!

6a. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 6 months from the last time I did so."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

7a. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

8a. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

9a. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3B

Interviewer: If

a) has been 3 years or less since completion of treatment,

b) participant was not adherent at baseline

e) AND has not done a symptom history since baseline

ask all of the questions on this page!!!!

6b. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 6 months who will ask me about any symptoms or problems related to breast cancer."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

7b. How much control do you have over going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

8b. Going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

9b. Most people who are important to you think you should go to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3C

Interviewer: If

a) it has been more than 3 years since completion of treatment,

b) participant was adherent at baseline

c) OR participant has done a symptom history since baseline

ask all of the questions on this page!!!!

6c. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 12 months from the last time I did so."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

7c. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

8c. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

9c. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 3D

Interviewer: If

a) has more than 3 years since completion of treatment.

b) participant was not adherent at baseline

c) AND has not done a symptom history since baseline
ask all of the questions on this page!!!!

6d. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 12 months who will ask me about any symptoms or problems related to breast cancer."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

7d. How much control do you have over going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

8d. Going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer will be

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

9d. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 4
BSE Adherence, Intention & Behavioral Control

1. Do you know how to do a breast self-exam?

☐ Yes ☐ No ☐ Not sure

2. How confident are you that you are able to do a breast self-exam correctly?

☐ Very confident
☐ Fairly confident
☐ A little confident
☐ Not at all confident

3. Since the last interview, has your doctor recommended that you do a breast self-exam (check your own breasts)?

☐ Yes ☐ No ☐ Not sure

4. Since the last interview, have you done a breast self-exam?

☐ Yes ☐ No ☐ Not sure

5. When was your last breast self-exam? Date _____

☐ Within the past week
☐ Within the past month
☐ Within the past 3 months
☐ Within the past 6 months
☐ Within the past year
☐ More than 1 year ago
☐ Not sure

6. How often do you perform breast self-examination (BSE)?

☐ Never
☐ At least once a day
☐ Once a week
☐ Twice a month
☐ Once a month
☐ Once every other month (six times a year)
☐ Two or three times a year
☐ Once a year
☐ When I have symptoms or problems

7. How much do you agree or disagree with this statement: "I intend to do breast self exam every month?"

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

8. How much control do you have doing breast self-exam every month?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

9. Doing breast self-exam every month would be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

10. Most people who are important to you think you should do a breast self-exam every month.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 5
Pelvic Exam/Pap Test Adherence, Intention & Behavioral Control

Interviewer: *Was participant adherent to Pelvic Exam/Pap Test in baseline interview?* ☐ *Yes* ☐ *No*

1. Since the last interview, has your doctor recommended that you have a pelvic exam and pap test?

☐ Yes ☐ No ☐ Not sure

2. Since the last interview, have you had a pelvic exam or pap test?

☐ Yes ☐ No ☐ Not sure

If yes, when? _____

3. Was this pelvic exam/pap test not routine (you had it because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

4. Do you have an appointment to have a pelvic exam and pap test?

☐ I have an appointment When? _____

☐ I have tried to make an appointment recently but I do not have one

☐ I have no appointment

Section 5A

Interviewer: If

a) participant was adherent at baseline

b) OR participant has had a pap test/pelvic exam since baseline

ask all of the questions on this page!!!!

5a. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test at least 12 months from the date of my last pelvic exam/pap test."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

6a. How much control do you have over having a pelvic exam and pap test at least 12 months from the date of your last one?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

7a. Having a pelvic exam and pap test at least 12 months from the date of your last one will be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

8a. Most people who are important to you think you should have a pelvic exam and pap test at least 12 months from the date of your last one.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 5B

Interviewer: If participant was not adherent at baseline AND has not had a pelvic exam/pap test since baseline, ask all of the questions on this page!!!

5b. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test sometime in the next 12 months."

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

6b. How much control do you have over having a pelvic exam and pap test sometime in the next 12 months?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

7b. Getting your next pelvic exam and pap test sometime in the next 12 months will be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

8b. Most people who are important to you think you should have a pelvic exam and pap test sometime in the next 12 months.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

Section 6
Other Follow-up Tests & Care

1. Since the last interview, have you had other types of follow-up tests? **Select all that apply.**

☐ CT scan or CAT scan (Computed tomography scan: A computerized x-ray procedure that produces cross-sectional images of the body.

☐ Ultrasound (also known as a sonogram, this technique uses sound waves to make pictures of the body organs and obtain images for medical diagnosis

☐ MRI (Magnetic resonance imaging: A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.

☐ X-rays (electromagnetic radiation used to produce images of bones, organs, and internal tissues)

☐ Blood tests

☐ Bone scans (A technique to create images of bones on a computer screen or on film after an injection of a small amount of radioactive material)

☐ Other _____

Section 7
Breast Cancer Surveillance Behavioral and Control Beliefs

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

The first set of questions asks about the follow-up care you may be receiving since you have completed breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
1.	I would probably not have follow-up care unless I had some breast symptoms or discomfort.	1	2	3	4	5
2.	Those people who are close to me will benefit if I have regular breast cancer follow-up care.	1	2	3	4	5
3.	If follow-up care finds a problem, whatever is there will probably be too far along to do anything about it anyway.	1	2	3	4	5
4.	I would be more likely to have regular follow-up care if my doctor told me how important it is.	1	2	3	4	5
5.	Regular follow-up care is too expensive for me.	1	2	3	4	5
6.	I don't have time for regular follow-up care.	1	2	3	4	5
7.	Regular follow-up care gives me a feeling of control over my health.	1	2	3	4	5
8.	If I eat a healthy diet, I will lower my risk of getting breast cancer far enough that I probably do not need regular follow-up care.	1	2	3	4	5
9.	Regular follow-up care gives me peace of mind over my health.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
10.	I would probably not have regular follow-up care if my doctor seemed to doubt I really needed it.	1	2	3	4	5
11.	Regular follow-up care causes me unnecessary worry.	1	2	3	4	5
12.	I am afraid to have regular follow-up care because I might find out something is wrong.	1	2	3	4	5

The next set of questions refer to feelings about follow-up care after breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
13.	I would be ashamed if follow-up care found that I have breast cancer again.	1	2	3	4	5
14.	Other people would view me negatively if follow-up care found that I had breast cancer again.	1	2	3	4	5
15.	I would be angry if follow-up care found that I had breast cancer again.	1	2	3	4	5
16.	I would be frightened if follow-up care found that I had breast cancer again.	1	2	3	4	5
17.	I would not be able to handle it emotionally if follow-up care found that I had breast cancer again.	1	2	3	4	5
18.	I would feel a sense of hopelessness and despair if follow-up care found that I had breast cancer again.	1	2	3	4	5

The next set of questions refer to mammograms and breast self-exams.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
19.	Having a mammogram is painful.	1	2	3	4	5
20.	Having a mammogram is embarrassing.	1	2	3	4	5
21.	If I receive a clinical breast exam from a doctor or nurse, I don't need to have a mammogram.	1	2	3	4	5
22.	If I do breast self-exam (check my own breasts), I don't need to have a mammogram.	1	2	3	4	5
23.	The results of mammograms are not trustworthy.	1	2	3	4	5
24.	Having a mammogram exposes me to unnecessary radiation.	1	2	3	4	5
25.	I am uncomfortable doing breast self-exam (checking my own breasts) because since I was treated for cancer, I'm not sure if what I'm feeling during the exam is normal or not.	1	2	3	4	5
26.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to look at my breasts since being treated for cancer.	1	2	3	4	5
27.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to touch my breasts since being treated for cancer.	1	2	3	4	5

Section 8
Social Influence/Normative Beliefs

Think about how much you agree or disagree with each of the following statements about follow-up care after breast cancer treatment. Please indicate how much you agree or disagree with the following statements using the key below

- 1=Strongly disagree**
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly Disagree	Moderately Disagree	Undecided / Not sure	Moderately Agree	Strongly Agree
1.	I have talked to or heard from breast cancer survivors who have regular follow-up care.	1	2	3	4	5
2.	I have talked to or heard from breast cancer survivors who benefit from regular follow-up care.	1	2	3	4	5
3.	I have received information about regular follow-up care that is useful to me as a Black survivor.	1	2	3	4	5
4.	I have received trustworthy information about regular follow-up care.	1	2	3	4	5
5.	I have talked to or heard from friends think I should have regular follow-up care.	1	2	3	4	5
6.	I have talked to or heard from my spouse or partner who thinks I should have regular follow-up care. <i>Not applicable</i>	1	2	3	4	5
7.	I have talked to or heard from family members who think I should have regular follow-up care.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided/ Not sure	Moderately agree	Strongly agree
8.	I have talked to or heard from people in my church or house of worship who think I should have regular follow-up care. <i>Not applicable</i>	1	2	3	4	5
9.	I have talked to or heard from my doctors or other healthcare providers who think I should have regular follow-up care.	1	2	3	4	5
10.	I have talked to or heard from other breast cancer survivors think I should have regular follow-up care.					
11.	I have talked to or heard from other Black women think I should have regular follow-up care.	1	2	3	4	5
12.	Most people who are important to me think I should have regular follow-up care.	1	2	3	4	5

Section 9
Breast Cancer Surveillance Knowledge Questionnaire

Please answer the following questions True, False, or Not sure.

1.	Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
2.	Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
3.	Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
4.	Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
5.	Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
6.	Breast cancer survivors only need to have physical exams about once a year after they have completed breast cancer treatment.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
7.	Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
8.	Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
9.	Women diagnosed with breast cancer need to examine their own breasts every day.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
10.	Chest pain and problems with breathing can be signs of breast cancer recurrence.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure

Section 10
Perceived Breast Cancer Recurrence Risk

1. On a scale of 0 to 100 where 0 means “no chance” and 100 means “guaranteed to happen,” how would you rate your chances of getting breast cancer again? _____
2. What do you think your chances are of being diagnosed with breast cancer again?
 - ☐ Very low
 - ☐ Low
 - ☐ Average
 - ☐ High
 - ☐ Very high
 - ☐ Not sure
3. On a scale of 0 to 100 where 0 means “not bad at all” and 100 means “the worst possible situation”, how bad would it be if you were to get breast cancer again? _____
4. On a scale of 0% to 100%, what percentage of all breast cancer survivors do you think will get breast cancer again? _____
5. Compared to other women who have had breast cancer, what do you think your chances are of being diagnosed with breast cancer again?
 - ☐ I am at much less risk than others
 - ☐ I am at somewhat less risk than others
 - ☐ My risk is about the same as others
 - ☐ I am at somewhat higher risk than others
 - ☐ I am at much higher risk than others
 - ☐ Not sure
6. How worried are you about getting breast cancer again?
 - ☐ Extremely worried
 - ☐ Moderately worried
 - ☐ Undecided/not sure
 - ☐ A little worried
 - ☐ Not at all worried
7. What do you think your chances are of getting a new cancer of some other type?
 - ☐ I am at much less risk than others
 - ☐ I am at somewhat less risk than others
 - ☐ My risk is about the same as others
 - ☐ I am at somewhat higher risk than others
 - ☐ I am at much higher risk than others
 - ☐ Not sure
8. How worried are you about getting a new cancer of some other type?
 - ☐ Extremely worried
 - ☐ Moderately worried
 - ☐ Undecided/not sure
 - ☐ A little worried
 - ☐ Not at all worried

9. What do you think your chances are of developing heart disease (high blood pressure, stroke, heart attack, etc.)?

- ☐ I am at much less risk than others
- ☐ I am at somewhat less risk than others
- ☐ My risk is about the same as others
- ☐ I am at somewhat higher risk than others
- ☐ I am at much higher risk than others
- ☐ Not sure
- ☐ I have already been diagnosed with heart disease

10. How worried are you about developing heart disease?

- ☐ Extremely worried
- ☐ Moderately worried
- ☐ Undecided/not sure
- ☐ A little worried
- ☐ Not at all worried
- ☐ I have already been diagnosed with heart disease

Section 11
Genetic Testing Awareness and Interest

1. How much have you heard or read about genetic testing for breast cancer risk?

- ☐ Almost Nothing
- ☐ Relatively Little
- ☐ A Fair Amount
- ☐ A lot

2. At the present time, how interested are you in getting genetic testing for breast cancer risk?

- ☐ Not at all interested
- ☐ Slightly interested
- ☐ Moderately interested
- ☐ Very interested

3. Now that such a test is currently available, which of the following best describes your intentions?

- ☐ I have already donated a blood sample for genetic testing.
- ☐ I plan to take the test as soon as possible (within the next 30 days).
- ☐ I plan to take the test sometime in the near future (within the next 6 months).
- ☐ I do not plan to take the test in the near future (not within the next 6 months).
- ☐ I do not plan to take the test at all.

Time 3
(13 -month follow-up assessment)

Section 1. Breast Cancer Surveillance Adherence and Intention

Section 2. Other follow-up Tests and Care

Section 3. Impact of Events Scale

Section 4. Exposure to Mammography-Related Information

Section 1
Breast Cancer Surveillance Adherence and Intention

Your last interview was on _____

A. Mammography

1. Since your last interview, have you had a mammogram?

☐ Yes ☐ No ☐ Not sure

2. How many have you had?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

3. Were any of these mammograms not routine (just a check-up) _____

4. Do you have an appointment to have a mammogram?

☐ I have an appointment Date _____
☐ I have tried to make an appointment but I do not have one
☐ I have no appointment

Interviewer: If participant has had a mammogram since last interview:

5a. How much do you agree or disagree with this statement: "I intend to have a mammogram at least 12 months from the date of my last mammogram."

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

Interviewer: If participant has not had a mammogram since last interview:

5b. How much do you agree or disagree with this statement: "I intend to have a mammogram sometime in the next 12 months."

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

Your last interview was on _____

B. Physical examination

1. Since your last interview, have you had a physical examination? (*physical examination is an evaluation of the body and its functions using inspection, feeling with the hands, tapping with the fingers, and listening*)?

☐ Yes ☐ No ☐ Not sure

2. How many have you had?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

3. Were any of these examinations not routine (you went because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

4. Do you have an appointment to have a physical examination?

☐ I have an appointment When? _____
☐ I have tried to make an appointment within the past month but I do not have one
☐ I have no appointment

Interviewer: If it has been 3 years or less since participant completed treatment AND has had a physical exam since last interview:

5a. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 6 months from the date of my last exam."

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

Interviewer: If it has been 3 years or less since participant completed treatment AND has not had a physical exam since last interview:

5b. How much do you agree or disagree with this statement: "I intend to have a physical examination some time in the next 6 months"

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

Interviewer: If it has been more than 3 years since participant completed treatment and participant has had a physical exam since last interview:

5c. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 12 months from the date of my last exam."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

Interviewer: If it has been more than 3 years since participant completed treatment and participant has not had a physical exam since last interview:

5d. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 12 months."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

Your last interview was on _____

C. Symptom History

1. Since your last interview, has a doctor asked you about any symptoms or problems related to breast cancer?

☐ Yes ☐ No ☐ Not sure

2. How many times has a doctor asked you about symptoms or problems related to breast cancer?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

3. Were any of these discussions not routine (you had the discussion because you had specific symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

4. Do you have an appointment to discuss any symptoms or problems?

☐ I have an appointment When? _____
☐ I have tried to make an appointment within the past month but I do not have one
☐ I have no appointment

Interviewer: If it has been 3 years or less since participant completed treatment AND has had a symptom history since last interview:

5a. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 6 months from the last time I did so."

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

Interviewer: If it has been 3 years or less since participant completed treatment AND has not had a symptom history since last interview:

5b. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer some time in the next 6 months"

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

Interviewer: If it has been more than 3 years since participant completed treatment and participant has had a symptom history since last interview:

5c. How much do you agree or disagree with this statement: “I intend to see a doctor who will ask me about symptoms or problems related to breast cancer at least 12 months from the date of my last exam.”

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

Interviewer: If it has been more than 3 years since participant completed treatment and participant has not had a symptom history since last interview:

5d. How much do you agree or disagree with this statement: “I intend to see a doctor who will ask me about symptoms or problems related to breast cancer sometime in the next 12 months.”

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Not sure/undecided
- ☐ Agree
- ☐ Strongly agree

Your last interview was on _____

D. Breast Self-Examination

1. Do you know how to do a breast self-exam (check your own breast)?

☐ Yes ☐ No ☐ Not sure

2. How confident are you that you are able to do a breast self-exam correctly?

☐ Very confident
☐ Fairly confident
☐ A little confident
☐ Not at all confident

3. Since your last interview, have you done a breast self-exam?

☐ Yes ☐ No ☐ Not sure

4. When was your last breast self-exam? Date _____

☐ Within the past week
☐ Within the past month
☐ Within the past 3 months
☐ Within the past 6 months
☐ Within the last year
☐ More than 1 year ago
☐ Not sure

5. How often do you perform breast self-examination (BSE)?

☐ Never
☐ At least once a day
☐ Once a week
☐ Twice a month
☐ Once a month
☐ Once every other month (six times a year)
☐ Two or three times a year
☐ Once a year
☐ When I have symptoms or problems

6. How much do you agree or disagree with this statement: "I intend to do breast self exam every month?"

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree

Your last interview was on _____

E. Pelvic Exam/Pap test

1. Since your last interview, have you had a pelvic exam and pap test?

☐ Yes ☐ No ☐ Not sure

2. How many have you had?

☐ None ☐ 1 ☐ 2 ☐ 3 or more

3. Were any of these pelvic exams/pap tests not routine (you had it because you had symptoms or problems)?

☐ Yes ☐ No ☐ Not sure

4. Do you have an appointment to have a pelvic exam?

☐ I have an appointment Date _____
☐ I have tried to make an appointment within the past 6 months but I do not have one
☐ I have no appointment

Interviewer: Ask if participant has had a pap test/pelvic exam since last interview

5a. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test at least 12 months from the date of my last pelvic exam/pap test."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Interviewer: Ask if participant has not had a pap test/pelvic exam since last interview

5b. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test sometime in the next 12 months."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2
Other Follow-up Tests & Care

1. Since the last interview, have you had other types of follow-up tests? **Select all that apply.**

☐ CT scan or CAT scan (Computed tomography scan: A computerized x-ray procedure that produces cross-sectional images of the body.

☐ Ultrasound (also known as a sonogram, this technique uses sound waves to make pictures of the body organs and obtain images for medical diagnosis

☐ MRI (Magnetic resonance imaging: A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.

☐ X-rays (electromagnetic radiation used to produce images of bones, organs, and internal tissues)

☐ Blood tests

☐ Bone scans (A technique to create images of bones on a computer screen or on film after an injection of a small amount of radioactive material)

☐ Other _____

Section 3
Impact of Events Scale

I'm going to read you a list of comments made by people about stressful life events. Using the scale 0=not at all, 1= rarely, 3=sometimes, and 4=often, please indicate how frequently these comments were true for you about breast cancer DURING THE PAST WEEK, INCLUDING TODAY.

0=Not at all**1=Rarely****3=Sometimes****5=Often**

		Not at all	Rarely	Sometimes	Often
1.	Thought about breast cancer when I didn't mean to.	0	1	3	4
2.	I avoided letting myself get upset when I thought about it or was reminded of breast cancer.	0	1	3	4
3.	I tried to remove breast cancer from memory.	0	1	3	4
4.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about breast cancer that came into my mind.	0	1	3	4
5.	I had waves of strong feelings about breast cancer.	0	1	3	4
6.	I stayed away from reminders about breast cancer.	0	1	3	4
7.	I had dreams about breast cancer.	0	1	3	4
8.	I felt as if breast cancer was unreal.	0	1	3	4
9.	I tried not to talk about breast cancer.	0	1	3	4
10.	Pictures about breast cancer popped into my mind.	0	1	3	4
11.	Other things kept making me think about breast cancer.	0	1	3	4
12.	I was aware that I had a lot of feelings about breast cancer but I didn't deal with them.	0	1	3	4
13.	I tried not to think about breast cancer.	0	1	3	4
14.	Any reminder brought back feelings about breast cancer.	0	1	3	4
15.	My feelings about breast cancer were kind of numb.	0	1	3	4

Section 4
Exposure to mammography-related information

We would like to know how much you have heard about breast cancer and mammograms in the past 24 months. Please tell us if you have heard about breast cancer and mammograms from the following sources using the key below

1=Not at all

2= A little

3= Some

4=A lot

How much have you heard about breast cancer and mammograms from:

		Not at all	A little	Some	A lot
1.	Health care providers	1	2	3	4
2.	Family members	1	2	3	4
3.	Friends	1	2	3	4
4.	Co-workers	1	2	3	4
5.	Your church	1	2	3	4
6.	A community organization to which you belong (such as a sorority or volunteer group)	1	2	3	4
7.	Television	1	2	3	4
8.	Radio	1	2	3	4
9.	Books	1	2	3	4
10.	Magazines	1	2	3	4
11.	Newspapers	1	2	3	4
12.	Brochures	1	2	3	4
13.	The internet	1	2	3	4
14.	E-mails	1	2	3	4
15.	Cancer education programs you have attended	1	2	3	4
16.	Cancer awareness organizations	1	2	3	4

In the past 13 months:

17. Have you heard about a family member diagnosed with breast cancer?

☐ Yes ☐ No

18. Have you heard about a friend diagnosed with breast cancer?

☐ Yes ☐ No

19. Have you heard about a celebrity or public figure diagnosed with breast cancer?

☐ Yes ☐ No

Appendix F

DEVELOPMENT OF AN INTERVENTION TO INCREASE BREAST CANCER SURVEILLANCE AMONG AFRICAN AMERICAN BREAST CANCER SURVIVORS

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Women diagnosed with breast cancer are at considerable risk for breast cancer recurrence and at elevated risk for developing a second primary breast cancer compared to women in the general population. Thus, breast cancer survivors represent a high-risk population for whom careful breast cancer surveillance and follow-up care is a priority. There are disparities in surveillance such that African-American (AA) survivors were approximately half as likely to have a mammogram compared to White survivors. It has also been reported that duration of medical follow-up care for AA survivors was significantly shorter than that of White survivors. These findings suggest that the promotion of recommended breast cancer surveillance among AA survivors is an area warranting special attention.

The objectives of the current Idea Award are: 1) to evaluate the impact of a peer-led survivor surveillance intervention on breast cancer surveillance intention and adherence (mammography, BSE, pelvic exam, physical examination, patient symptom history) among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mediational pathways through which the intervention impacts surveillance intention and adherence.

In order to reach these objectives, we have developed “Survivors in Spirit,” a faith-based and peer-led educational program. Presentations include: 1) an inspirational introduction, 2) testimony by at least one breast cancer survivor about her cancer detection, survival and the importance of regular surveillance; 3) review of breast cancer recurrence facts by a lay health educator; 4) discussion of concerns and myths about breast cancer recurrence and screening/surveillance that are salient among AAW; 5) review of guidelines for surveillance as established by the American Society of Clinical Oncologists; and 6) “hands-on” breast self-exam instruction using the “grid” method, which emphasizes examination of not only the breast but adjacent areas (e.g., chest, armpit).

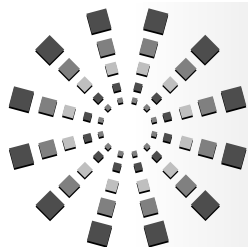
In developing “Survivors in Spirit,” we conducted a preliminary qualitative study that included key informant interviews of 10 AA breast cancer survivors. Survivors reported a number of factors that motivated or deterred them in obtaining follow-up care: a desire to maintain good health, worry and fear about recurrence, support from health care providers, familial relationships, lack of support from family and friends, relationships with other survivors, religious or spiritual faith, lack of information about post-treatment follow-up care, medical care costs and limited access to quality healthcare. These data were used to further develop the “Survivors in Spirit” intervention. To date, we have conducted two 5-hour training sessions during which we trained 8 breast cancer survivors (referred to as survivors speakers) and 15 lay health educators. All volunteers completed

training pre-tests and post-tests of breast cancer recurrence knowledge. Overall, knowledge scores increased following training sessions (pre-test mean=58% correct; post-test mean=80% correct). “Survivors in Spirit” represents a promising strategy to increase breast cancer surveillance among AA survivors.

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Appendix G



Hayley S. Thompson, PhD

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Posttreatment Breast Cancer Surveillance and Follow-up Care Experiences of Breast Cancer Survivors of African Descent

An Exploratory Qualitative Study

KEY WORDS

Breast cancer recurrence

Breast cancer surveillance

Breast cancer survivors

Racial/ethnic disparities

Breast cancer survivors are at considerable risk for breast cancer recurrence and at higher risk of developing a new breast cancer compared with women never diagnosed. It is recommended that survivors undergo careful breast cancer surveillance as cancers detected early are more treatable. However, data indicate that surveillance among African American survivors, particularly mammography, is lower than that of white survivors. There is little published work focusing on general experiences of posttreatment breast cancer surveillance among survivors of African descent. In the current qualitative pilot study, key informant interviews were conducted in order to explore the following: (1) the extent of posttreatment surveillance information provided to or obtained by survivors of African descent; (2) the actual follow-up care received by survivors in the past year; and (3) factors that are either motivators of or barriers to care. Participants were 10 African American and African Caribbean breast cancer survivors. Survivors reported a number of factors that motivated them in obtaining follow-up care: a desire to maintain good health, concern about recurrence, support from healthcare providers, familial relationships, relationships with other survivors, and religious/spiritual faith. Survivors also reported barriers to care: fear of recurrence, low support from family and friends, lack of information about posttreatment follow-up care, and medical care costs. These results represent formative work that may inform similar studies examining factors in breast cancer surveillance and follow-up care in larger samples of survivors of African descent.

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Breast cancer survivors are at considerable risk for local breast cancer recurrence. Local recurrence rates among breast cancer patients diagnosed primarily with in situ, stage I or stage II disease and receiving surgical treatment and adjuvant therapy are reported at 5% to 10% at 5-year follow-up and 10% to 15% at 10-year follow-up.¹⁻⁵ Breast cancer survivors are also 2 to 6 times more likely to develop a second primary breast cancer in the contralateral breast compared with women in the general population.^{6,7} Thus, breast cancer survivors represent a high-risk population for whom careful breast cancer surveillance and follow-up care is a priority. Evidence indicates that locally recurrent or contralateral breast cancers found at an early stage, specifically those that are noninvasive or characterized by smaller tumor sizes, are associated with a better prognosis compared with more advanced cancers.^{8,9}

Routine screening, particularly mammography and physical examination, has been found to detect local recurrences and contralateral breast cancers at earlier stages,⁹⁻¹² but data suggest that breast cancer survivors underuse surveillance modalities, particularly mammography. Across several recent studies, 22% to 45% of breast cancer reported no mammogram during intervals ranging from 2 to 4 years.^{13,14} In one study, African American (AA) survivors were approximately half as likely to have a mammogram compared with white survivors.¹⁵ It has also been reported that duration of medical follow-up care for AA survivors was significantly shorter than that of white survivors (53 vs 65 months, respectively).¹⁶ These findings suggest that the promotion of posttreatment breast cancer surveillance among survivors of African descent is an area warranting special attention.

Surprisingly, there is little published work on predictors of posttreatment breast cancer surveillance and follow-up care among breast cancer survivors of any ethnicity or race. Two models may guide the investigation of these predictors. The first is Andersen's Behavioral Model for Health Services Utilization (BMHSU),¹⁷ which outlines the role of population characteristics, the healthcare system, and the external

environment in explaining and predicting health behaviors. In the current research, we have focused on population characteristics: (a) predisposing factors (eg, demographic characteristics, health beliefs), (b) enabling resources (eg, social relationships, access to healthcare, ability to pay for healthcare), and (c) need factors (eg, perceived and evaluated need, such as physician recommendation) (see Figure 1).

There is evidence that BMHSU factors are predictors of surveillance and follow-up care among breast cancer survivors. For example, physician recommendation, a need factor described by the BMHSU, is associated with participation in mammography among survivors.¹⁴ Enabling factors are also associated with mammography use among survivors, such as employment status and receiving treatment at a breast center.¹⁴ Predisposing factors that have been identified are largely limited to diagnostic and treatment variables, such as method of initial cancer detection, stage of diagnosis, and type of treatment received.^{13,14,18} There are no published data on role of attitudinal predisposing factors that influence surveillance among breast cancer survivors. However, such factors have been reported to be associated with mammography screening among healthy AA women in the general population and these findings may provide insight into mammography among survivors. Among AA women in the general population, breast cancer knowledge was significantly associated with past adherence to mammography as well as intention to have a mammogram.¹⁹⁻²² Perceived benefits of mammography have also been reported to be salient among AA women, such as obtaining peace of mind and the early detection of cancer.²³ Some perceived barriers were also significantly more likely to be reported by AA women compared with whites, such as increased cancer-related worry and fear of radiation exposure during a mammogram.²⁴⁻²⁶

The second model that may guide the investigation of predictors of surveillance and follow-up care is Baldwin's Afrocentric model for describing AA women's participation in breast and cervical cancer screening.²⁷ A primary component of this model is the African worldview: the extent to which

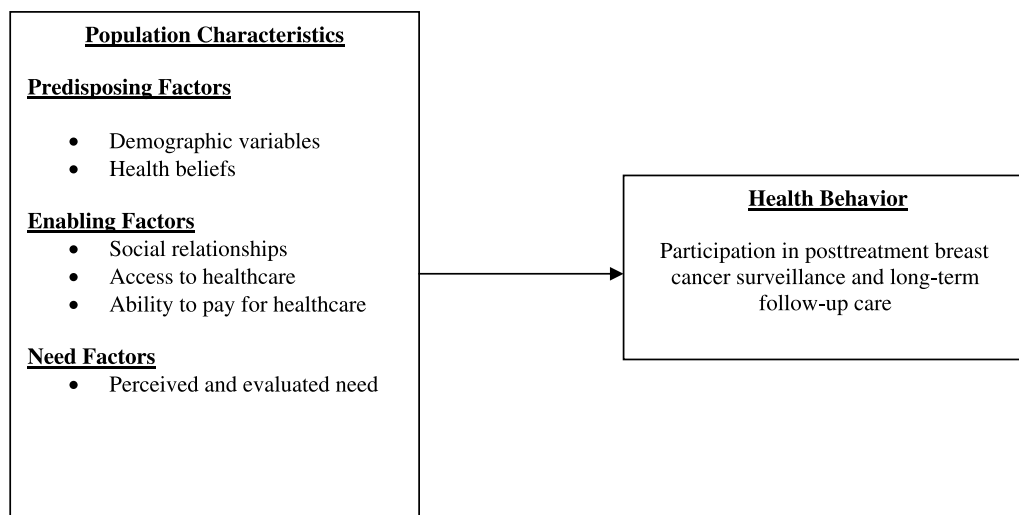


Figure 1 ■ Andersen's Behavioral Model for Health Services Utilization.

one's cultural traditions and values influence daily life. Based on this Afrocentric model, it is plausible that sociocultural factors salient among survivors of African descent may be associated with surveillance. One such factor is collectivism, or the belief that members of one's cultural group and family play a major role in shaping individual behavior, including health behaviors such as mammography.²⁸ Evidence for the role of collectivism in breast cancer-related preventive care was reported by Hughes et al,²⁹ who found that familial interdependence influenced participation in genetic testing for breast cancer risk. A second sociocultural factor encompasses religious and spiritual beliefs, the salience of which is well-documented in African cultures. Mitchell et al³⁰ found that AA women in the general population were more likely to hold religious beliefs related to breast cancer. Additionally, God locus of control and spiritual locus of health control were associated with adherence to breast cancer screening in undiagnosed AA samples.^{31,32} Such sociocultural factors may also influence surveillance among breast cancer survivors.

The current study attempted to address the gap in the literature on posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent. Both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) recommend that following primary treatment, breast cancer survivors participate in annual mammography and a schedule of frequent physical examinations and symptom histories.^{33,34} ASCO also recommends monthly breast self-examination (BSE) and regular pelvic examination and Papanicolaou test.^{33,34} In the current qualitative pilot study, key informant interviews were conducted with AA and African Caribbean (AC) breast cancer survivors to explore the following: (1) the extent of posttreatment surveillance knowledge among survivors; (2) the actual follow-up care received by survivors in the past year; and (3) factors that serve as either motivators of or barriers to care. Motivators and barriers were further categorized as predisposing, enabling, and need-related according to the BMHSU.

■ Methods

Participants

Participants were 10 AA/AC female breast cancer survivors residing primarily in the New York City area. Eligibility criteria included self-identification as black or of African descent, being age 20 years or older, completion of primary treatment of breast cancer at least 1 year before study participation (primary treatment was defined as any combination of surgery, radiotherapy and chemotherapy), and having a single breast cancer diagnosis with no diagnosis of recurrent or contralateral breast cancer.

Assessment

Participants were first asked questions about sociodemographic variables, including age, ethnicity, and education

level. They were also asked about their breast cancer treatment, including time of diagnosis, type of primary treatment, and the date primary treatment ended. All participants completed key informant interviews that were structured according to a model outlined by Wengraf.³⁵ In this model, semistructured in-depth interviews are used to build and test descriptive and explanatory models of social and psychological experience. Features of a semistructured depth interview include the following: (1) it is fundamentally a research interview designed for the purpose of expanding knowledge; (2) as a research interview, it is a unique type of conversational interaction influenced by both interviewer and interviewee characteristics; (3) it is designed with interview questions prepared in advance but open in such a way that requires some interviewer improvisation during the interview; and (4) it is in-depth in the sense that it assumes that social and behavioral phenomena are more complex than they often appear. The structure of a semistructured depth interview is guided by the CRQ-TQ-IQ model described by Wengraf.³⁵ In this model, a central research question (CRQ) is identified and explicated through several theory questions (TQs) to which responses are sought. Such TQs are conceptual-framework-dependent and formulated in theoretical language. Theory questions guide the development of interview questions (IQs) that represent the operationalization of TQs in language that is appropriate for use with study participants. To obtain information relevant to a TQ, interviewees are asked to respond to IQs.

The CRQ of the current study was "What is the experience of posttreatment breast cancer surveillance and follow-up care among breast cancer survivors of African descent?" This CRQ was followed by 3 broad TQs: (1) What is the extent of AA/AC survivors' knowledge of surveillance and follow-up care guidelines? (example IQs: After your treatment, what were you told about the long-term follow-up care you need? What was your understanding of the purpose of long-term follow-up care?); (2) In what type of surveillance and follow-up care do AA/AC survivors participate? (example IQs: Who do you see for your long-term follow-up care? What follow-up care have you received in the past year?); (3) What factors serve as either facilitators of or barriers to AA/AC survivors' follow-up care? (example IQs: What has motivated you to get the care you have received so far? How much does your family motivate you? What, if anything, has kept you from getting long-term follow-up care? How much do medical costs keep you from getting care? How does religious or spiritual faith affect your follow-up care?). Participants were asked to base their answers on their own experience as well as their observations of the experiences of other AA/AC survivors. In addition to responding to TQs and IQs, participants were also asked to separately respond to 3 close-ended items: (1) "I get enough information about breast cancer recurrence (getting breast cancer again) at my follow-up visits"; (2) "My emotional and psychological concerns are addressed at my follow-up visits"; and (3) "I feel reassured by my follow-up visits." Response options were based on a Likert-type scale from 1 (*strongly disagree*) to 4 (*strongly agree*).

Study Design, Procedures, and Analysis

The current study was exploratory, qualitative, and was intended to represent formative work in an understudied area: posttreatment breast cancer surveillance and follow-up care among breast cancer survivors of African descent. Participants were recruited through breast cancer patient support groups as well as volunteer pools of cancer education and outreach programs. Announcements were made at meetings of these groups by study staff, and survivors who expressed interest in participating in the study provided their contact information and were later contacted by staff. Eligibility was confirmed at that contact. Once eligible participants were identified and informed consent obtained, interviews were conducted either over the telephone or in person by trained, ethnically matched interviewers. All interviews were audiotaped and lasted between 30 and 60 minutes. Interviews were then fully transcribed. An open-coding strategy was used to identify common concepts across participant responses and to develop categories of responses for each TQ. Coding was facilitated by the Ethnograph V5.08 software package. Participant recruitment was ended after the 10th participant based upon findings that emerged during ongoing data analysis. These findings suggested that theoretical saturation had been reached such that no new or relevant dimensions were emerging from the data, and additional interviews from our potential pool of participants would not have yielded new insights.³⁶

■ Results

Participant Characteristics

Table 1 summarizes participants' background information, including information about their breast cancer treatment and follow-up care. Participants were between 38 and 63 years (mean age = 50.2; SD = 8.4). Five participants identified as AA, 4 identified as AC, and 1 self-categorized as both. In terms of breast cancer history, participants were between 1 and 6 years posttreatment (mean = 3.0 years; SD = 1.8). Nine participants were treated surgically, 9 underwent adjuvant radiation or chemotherapy (1 participant received chemotherapy as primary treatment), and 7 continued to take some type of hormonal therapy once primary treatment ended.

TQ1: What is the Extent of AA/AC Survivors' Knowledge of Surveillance and Follow-up Care Guidelines?

All participants except one reported that they were provided with specific recommendations about follow-up care after primary treatment ended. The most common recommendation reported from any physician with whom participants had contact was to increase the number of physician visits over the course of a year. More than half of the participants were advised to schedule physician visits every 3 to 6 months

❁ **Table 1 • Participant Characteristics, Treatment Information, and Physicians Providing Follow-up Care**

	n
Age	
35–49 years	5
50–59 years	3
≥60 years	2
Education level	
<High school	2
High school or GED	4
Associate's, Bachelor's, or graduate degree	4
Time since end of primary treatment	
1–2 years	5
3–4 years	3
5–6 years	2
Type of surgery	
Mastectomy	4
Breast-conserving surgery	5
Adjuvant therapy	
Radiation therapy	3
Chemotherapy	4
Both radiation and chemotherapy	2
Hormonal therapy (eg, Tamoxifen, Nalvodex)	7
Reported specialty of physicians seen for breast cancer surveillance	
Oncologist	5
Surgeon	6
Radiologist	4
Primary care physician	5
Gynecologist	5

immediately after treatment and then every 6 to 12 months as posttreatment time progressed.

TQ2: In What Type of Surveillance and Follow-up Care do AA/AC Survivors Participate?

In this sample, the mean number of physician visits in the past year was 6 (SD = 3.5; range = 2–15 visits). In these analyses, physician visits served as a proxy for symptom history discussions. When asked what type of physicians provided their follow-up care, most participants reported seeing several medical specialists, including oncologists, surgeons, primary care physicians, gynecologists, and radiologists. These data are presented in Table 1. The frequencies of other breast cancer surveillance strategies are presented in Table 2. The majority of participants (70%) both reported at least 2 physical examinations in the past year and were adherent to ASCO guidelines for physical examination. Although only 2 participants reported receiving specific mammography recommendations, almost all participants reported a mammogram in the past year. Similarly, most participants did not report receiving specific information about BSE but all reported practicing BSE, with approximately half practicing BSE monthly and the other half either overpracticing or underpracticing. Almost all participants reported a pelvic examination and Papanicolaou test in the

past year. Half of the participants also reported receiving extensive cancer surveillance, with the most common ones being blood tests, bone scans, and sonograms. Other tests included MRI, x-ray, PET scan, and CT scan.

Interestingly, most participants mentioned dietary change (eg, decrease in consumption of high-fat foods) and maintenance of a healthy weight as part of recommendations that they received regarding posttreatment follow-up care. However, there was some indication that although participant interest in dietary change was high, the information they were provided was too general. As one participant expressed:

One of the things that I find is a problem though is... it's trying to get a balance with nutrition and um, and linking it with oncology, you know, and I don't think it's readily available. You really have to go out and seek that part of it to me that is a part of the care or should be a part of the care. And to me it's not in there as much as it should be.

This statement represents the general consensus among participants that diet and nutrition as an area of posttreatment wellness is important and about which more specific information is desired.

TQ3a: What Factors Serve as Motivators of AA/AC Survivors' Follow-up Care?

Survivors reported a number of motivating factors in obtaining follow-up care: a desire to maintain good health, concern

about recurrence, support from healthcare providers, familial relationships, relationships with other survivors, and religious or spiritual faith. These motivating factors were further categorized as predisposing, enabling, or need-related (see Figure 2).

DESIRE TO MAINTAIN GOOD HEALTH

The desire to stay healthy, live a healthy life, or to live was most often cited first as a motivating factor in obtaining follow-up care. Follow-up care was often associated with early recurrence detection, and early detection was widely viewed as a key component of maintaining one's health. This is indicated in the following participant's statement:

I'm a firm believer that through early detection, you're going to alleviate a lot of problems. So, I think that continuous care is needed so in case there is a problem developing, we could, you know, address it early.

CONCERN ABOUT BREAST CANCER RECURRENCE

Concern about recurrence was cited as a factor that motivates participation in follow-up care. Participants indicated that such concern motivates them to obtain care because it fosters vigilance about health. For example:

I'm concerned that the breast cancer might come back. But that will make me go more to get the care. But at the same time, you know, I try to be mindful that it's not a journey that I would want to go on again because the second time around is definitely going to be worse than the first time. So, you know, I do try to do what's necessary, in order to avoid that experience again.

As this statement indicates, concern may be fueled by the memory of the first diagnosis and subsequent treatment, as well as anticipation of greater difficulty managing a second diagnosis. Interestingly, when asked about their perception of their recurrence risk, half of the participants stated that they believed their chances of getting cancer again were "none" or "zero." The other half acknowledged the possibility, stating "50/50" or that they weren't sure.

SUPPORT FROM HEALTHCARE PROVIDERS

Physician recommendation was often endorsed as a motivator of follow-up care participation. Recommendation was often not distinguished from personalized encouragement from physicians and participants' perceptions that their physicians genuinely cared about them as individuals. Participants indicated that they were more likely to keep appointments because they felt that their physicians were kind, trusted that their physicians acted in their best interests, and felt that their physicians took a personal and professional interest in them both physically and psychologically. For example:

To be honest, my doctor, his concern motivated me. He cares so much, I need to care. He showed that he cared so much.

❁ Table 2 • Participant-reported Breast Cancer Surveillance in the Past Year	
Frequency of Tests	n
Tests included in ASCO guidelines	
Physical examination	
1	3
2	4
≥3	3
Mammogram	
0	3*
1	7
Pelvic examination/Papanicolaou test	
0	2
1	7
2	1
BSE	
Daily	3
Monthly	6
Every other month	1
Other surveillance tests	
Blood tests	3
Sonogram	2
Bone scan	2
Other	5

ASCO indicates American Society of Clinical Oncology; BSE, breast self-examination.
*Two of these participants reported having an upcoming appointment for a mammogram and the third reported double mastectomy.

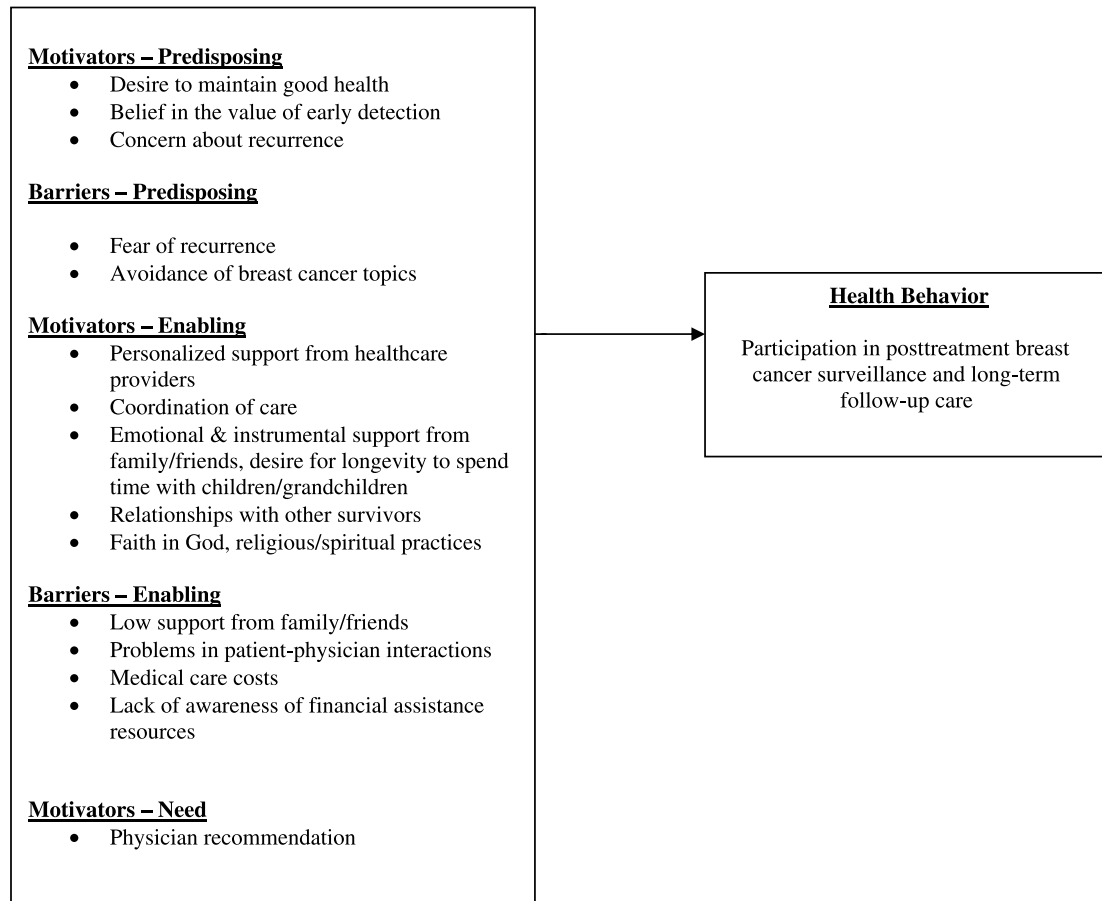


Figure 2 ■ Motivating and barrier factors categorized as predisposing, enabling, or need-related.

Although many participants reported that they were willing to participate in follow-up care and surveillance examinations based on their physicians' recommendations alone, they also reported that their physicians had a participatory style that involved them as a collaborator in their care.

Coordination of care was also a motivating factor. About half of the participants reported that the multiple physicians with whom they consulted also communicated with each other. Such communication appeared to bolster participants' confidence in the care received. Finally, nurses and health educators were also members of participants' care teams and, in some cases, provided information and support that was not received from a physician. For example:

In talking to the clinical trial nurse and having some kind of ongoing dialogue with her, I was able to ask her what were her recommendations. I felt that, um, I could have gotten that information from my doctor, but I didn't. But I was still able to get it.

FAMILIAL RELATIONSHIPS

The support of one's family was often endorsed as a motivating factor. Participants reported that they received both emotional and instrumental support from family members that encouraged them to obtain posttreatment follow-up care (eg, verbal expressions of support, accompanying participants to appoint-

ments). Participants also reported their strong emotional bond to family members as a motivating factor, specifically the desire to have a long life in order to spend more time with one's children and grandchildren. This is expressed in the following participant's statement:

My family, I can't even express. My children, my husband, my sister, they have all been there for me. What motivated me more to continue my check-up is because I have grandchildren. I would kind of like to see them grow up. So, I am very much motivated, myself, to get the proper care.

Follow-up care was also viewed as an opportunity to obtain more information about breast cancer and its outcomes. By doing so, participants believed they could keep their children and other family members informed about the disease.

RELIGIOUS OR SPIRITUAL FAITH

Almost all participants discussed faith in God as central to their lives posttreatment. In many instances, participants described a multidimensional and holistic view of breast cancer care that included medical, social, emotional, and spiritual foci.

My faith in God has played a big role in my follow-up care, even though, oh, um the doctors can take care of

the physical part of me but I need God for the spiritual part of me.

Other participants presented their faith as a form of coping, such that if a recurrence is detected, they felt confident that they could manage its challenges.

It plays a great part for me because, I am not saying because I pray and believe I will not get it again but if I get it again, my religious belief is that God, He knows that whatever He wants for me at this point, I am ready to accept. If it wasn't for Him, I wouldn't be here today. I think He steered me in the direction to finding it [the first breast cancer]. But if it happened to me, I could accept it a little more than the first time.

RELATIONSHIPS WITH OTHER BREAST CANCER SURVIVORS

Interactions with other survivors were reported as motivation to participate in follow-up care in 2 ways. First, the support received from other survivors was often reported as helpful.

If I am feeling a certain way, or if I am feeling low in spirit or something like that, I can speak to some of the other survivors who have gone through similar experiences. We help each other.

Relationships with breast cancer survivors was also a motivator because some participants felt it was important to be a role model to others by being particularly mindful of their health and care. This is demonstrated in the comment of a participant active in breast cancer education and outreach:

I also educate woman on breast health and I feel that I owe it to do it so then I have to follow up and take care of myself, so that my family and every one around me could see that it means something...you know, what I am saying is real and you know, I have to set an example.

TQ3b: What Factors Serve as Barriers to AA/AC Survivors' Follow-up Care?

Survivors also reported a number of barriers to follow-up care: fear of recurrence, low support from family and friends, lack of information about posttreatment follow-up care, and medical care costs. These barriers were also further categorized as predisposing, enabling, or need-related (see Figure 2).

FEAR OF BREAST CANCER RECURRENCE

Although concern about breast cancer recurrence may prompt participation in follow-up care, fear of being diagnosed again was specifically cited as a potential barrier to care. One participant described how fear may influence breast cancer survivors of African descent:

And sometimes some of them are scared to talk about their breast and some of them are fearful to go [for follow-up care] because they don't, like, if they had it [breast cancer] before they don't want to think they might have it again so they don't go, and things like that.

Some participants suggested that some survivors may blunt their worry and fear about a second breast cancer diagnosis by asserting that the breast cancer experience is "over" and of little relevance to one's life posttreatment. Toward this end, a survivor may avoid discussions about breast cancer and avoid those who were involved in her cancer care. For example:

I think also some people do want it to be over and you can bring some sort of finality to it if you are not seeing the same people as you did before.

LOW SUPPORT FROM FAMILY AND FRIENDS

Although 70% participants reported that support from family members was a strong motivating factor in obtaining follow-up care, 40% also reported mixed support from family and friends post-breast cancer treatment that was a potential barrier. A common theme was that significant others were uncomfortable with the participant's breast cancer experience or had not coped well with that experience. As one participant stated:

Actually, support from my family and friends was not that strong because they felt nothing and my family, some of them still can't come to terms with the fact that it [breast cancer] did happen to me.

In other instances, family and friends had different views of the controllability of breast cancer that informed their opinions about follow-up care. One Caribbean participant shared her experience:

My friends, well, it's a mixed thing. Some said nothing is wrong with me so I must not go and take the follow-up help. And some said go because, though I am a Christian, God said help those who help themselves. Yeah, so one side is telling me because I am a Christian I can't [be] sick. You know some people? And one side is telling me that because I am a Christian, I must do what I have to do.

LACK OF INFORMATION ABOUT POSTTREATMENT CARE

Participants frequently discussed lack of knowledge about the recommended follow-up care.

Yes, one of the things that I think is part of the problem is just lack of information. As I mentioned before, I have actually spoken to a couple of people, umm, you know in terms of the post situation... in terms of what I do and they were like, "Really? Why is all of that necessary?" And I was like, well this is what you should be getting, too. And they were like, "No the doctor said..." Like, one person had just finished chemo and radiation and said she wasn't seeing the doctor again for another year. And I was like, "You are supposed to go back." I said, "Call, do something," you know. So I think people are not as informed.

It was suggested that low knowledge was a function of patient-provider interactions in which survivors do not ask their physicians appropriate questions about care or are unassertive in obtaining this information.

Some people like to get information incrementally, on a need-to-know basis. And some doctors operate that way. You don't need to know and people accept that and I think that is a factor as well. In terms of...if you don't really know what you need to be doing or what you should be doing and you don't ask the right questions.

This response represents a belief reported by most participants that many AA/AC breast cancer survivors do not have access to adequate and up-to-date information about breast cancer care strategies.

MEDICAL CARE COSTS AND ACCESS

The cost of medical care was cited by almost all participants as a reason why AA/AC survivors may not be obtaining recommended follow-up. Costs were often linked to resources and it was reported that many survivors (1) are unaware of resources through which they might receive financial assistance or (2) are unable or unwilling to negotiate those bureaucratic aspects of those resources.

Close-ended Questions

Overall, participants reported high quality of follow-up care as indicated by responses to close-ended questions. Most participants agreed that, at follow-up visits, they get enough information about breast cancer recurrence at their follow-up visits (70%), their emotional and psychological concerns are addressed (70%), and that they feel reassured by follow-up visits (80%).

■ Discussion

The primary aim of this qualitative study was to explore the posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent. Guided by the CRQ-TQ-IQ model, key informant interviews were conducted to address several broad areas. The first area focused on knowledge about posttreatment surveillance. Consistent with ASCO and NCCN guidelines, the most common recommendation reported by participants was an increase in physical examinations. However, participants did not report receiving follow-up care recommendations regarding mammography or other types of care, such as breast self-examination. It is possible that recommendations for other surveillance tests were made to participants but these recommendations were not associated with a comprehensive strategy of follow-up care. Also, given the various medical providers participants reported seeing for follow-up care, it is unlikely that all recommendations were presented in a single physician visit, thereby decreasing the likelihood that participants perceived the recommendations as comprehensive strategy. However, low awareness of such a strategy may not have had a significant impact on follow-up care participation, as indicated by the second area of inquiry in key informant interviews focused on participation in follow-up care. Most participants

were adherent to ASCO and NCCN guidelines with the majority reporting a mammogram in the past year and reported 2 or more physical examinations in the past year. Overall, rates of follow-up care participation were high among these participants, inconsistent with previous work reporting racial disparities in care between AA and white survivors.¹⁵

The third broad area addressed by key informant interviews focused on factors related to follow-up care. Participants in this sample reported a number of motivators of follow-up care that were consistent with the BMHSU and Baldwin's Afrocentric model (see Figure 2). For example, there were several motivating and predisposing factors identified that could be categorized as health beliefs as outlined by the BMHSU. These factors include the desire to maintain good health, belief in the value of early detection, and concern about recurrence. Barriers that were also predisposing were identified, including fear of recurrence and avoidance of breast cancer topics. Fear of breast cancer recurrence, in particular, may be an area warranting further investigation in the survivor population as previous findings related to cancer fear are mixed. Cancer-related fear is related to both a lower and higher likelihood of breast cancer screening in the general population.³⁷ In their review of this topic, Consedine et al³⁷ cited data suggesting that fear of screening components (eg, mammography pain and radiation) is more strongly associated with screening nonadherence compared with fear of screening outcomes and undifferentiated cancer fear. Although the participants in this sample focused primarily on the screening outcome of recurrence diagnosis, future research may examine the impact of different types of cancer fear in depth.

Motivating factors that were also enabling were identified and several were categorized as social relationship variables as outlined by the BMHSU. These factors include personalized support from healthcare providers, support from family/friends, desire for longevity to spend time with children/grandchildren, and relationships with other survivors. These factors are not only consistent with the BMHSU but also with Baldwin's African worldview construct. For example, the finding that significant others were reported as playing a positive role in participation in care is consistent with the assertion that collectivism, or belief in the primacy of the family or cultural group, is important to AA/AC women's health beliefs and practices.^{38,39} However, significant others were also reported as a barrier to care to the extent that friends and family members may avoid addressing a survivor's breast cancer experience or do not foster a supportive environment for a survivor to discuss her experiences. These results are supported by findings that, among women in the general population, low social support is associated with lower adherence to breast cancer screening guidelines.⁴⁰⁻⁴² Although the association between social support and follow-up care has not been explored among breast cancer survivors, studies have shown that social constraints, defined as social conditions that cause one to feel unsupported by their social network when they are seeking social support,⁴³ are associated with poorer psychological outcomes among cancer patients.^{44,45}

The relationship between social support, social constraints, and posttreatment follow-up care is one deserving further attention.

Support from physicians was also reported as a motivating and enabling factor in follow-up care. Participants were motivated by what they perceived as personalized attention and interest. Additionally, participants cited support from other types of healthcare providers, including nurses and health educators, who served as both primary and secondary sources of support and information.

One motivating, enabling factor not described by the BMHSU but consistent with African worldview is faith that God will help one cope with recurrence, as well as the use of religious/spiritual practices, such as prayer, in coping with the threat of recurrence. Previous work on cancer beliefs among people of African descent reveals belief in God's power to both cause and cure cancer, the recognition of spiritual and religious practice in cancer progression, and the categorization of cancer as "God's will."^{46,47} It is not surprising, then, that spirituality/religiosity emerged as a motivator of participation in follow-up care.

Motivators and barriers consistent with enabling resources include coordination of care, medical care costs, and lack of awareness of financial assistance resources. These findings are similar to general-population breast screening findings showing that prohibitive medical care costs,⁴⁸ lack of health insurance coverage,⁴⁹ and lack of access to screening and other healthcare services^{50,51} are associated with nonadherence to mammography. Finally, a need-related motivating factor in follow-up care was physician recommendation. Again, this is similar to findings of other works on breast cancer screening in the general population as physician recommendation is consistently associated with adherence to mammography among AA women.^{23,52}

Limitations of the current study must be acknowledged. First, the generalizability of results may be restricted because participants were members of established breast cancer survivor networks, either as lay educators or support group members. As such, they may represent a subset of AA/AC breast cancer survivors who are generally more motivated to seek out a range of medical, social, and psychological resources available to breast cancer survivors. Furthermore, these participants were fairly well-educated, with 40% of the sample reporting post-secondary education. Results based on mammography in the general population show that women with high school or college-level educations are more likely to have had a mammogram compared with women with less education.^{53,54} This may partially explain why participants in this sample generally reported high rates of participation in breast cancer surveillance and follow-up care. Due to the relatively high level of participant involvement in care, the full range of possible barriers to surveillance and follow-up care may not be described here. Future research in this area should address the following issues: (1) the recruitment of larger and more sociodemographically diverse samples of AA/AC survivors; (2) the identification of participants from a range of community-based and hospital- or clinic-based sources; (3) the use of other forms of qualitative data

collection, such as focus groups; (4) the translation of qualitative data into quantitative measures that may be validated; and (5) the inclusion of standardized measures to assess factors that have been supported by previous research.

Despite the study's limitations, this research represents one of the first attempts to understand and describe the surveillance and follow-up care experiences of breast cancer survivors of African descent. Ultimately, this line of research may inform surveillance-focused interventions, such as patient-directed interventions, that focus on educating survivors about the nature of recurrence, their risk of recurrence, and the recommended guidelines for surveillance and follow-up. Such interventions may also focus on informing survivors of the resources related to obtaining financial assistance for this care. Other interventions that may be considered are those that are physician-directed and focused on enhancing physicians' communication skills and interpersonal style which may lead to improved relationships with AA/AC breast cancer survivors and may motivate participation in care. Another type of intervention may be social network-directed. A survivor may benefit from interventions that engage family and friends by (1) educating them about the breast cancer etiology, treatment, and posttreatment follow-up care and survivorship issues; (2) exploring and processing their cognitive and emotional reactions to the survivor's diagnosis and treatment; and (3) providing coaching in cancer-related communication skills that may reduce a survivor's social constraints.

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Appendix H

Training Lay Health Workers to Promote Post-Treatment Breast Cancer Surveillance in African American Breast Cancer Survivors: Development and Implementation of a Curriculum

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Abstract—*Background.* African American breast cancer survivors are less adherent to guidelines for post-treatment breast cancer surveillance compared to White survivors. Survivors in Spirit (SIS) is an intervention that addresses this problem through lay health workers (LHWs). *Methods.* African American women were trained as LHWs using a structured curriculum. Trainees' intervention knowledge was assessed before and after training. *Results.* There was a substantial increase in the mean percentage of correct items from pre- to post-test for the trainees as a group. *Conclusions.* LHWs can be effectively prepared to conduct interventions focusing on the complexities of breast cancer recurrence and surveillance.

Over the last decade, there has been a significant decrease in breast cancer-related mortality, due to earlier detection and improved treatment, making breast cancer survivors one of the largest groups of cancer survivors in the United States.¹ However, breast cancer survivors report many unmet information needs including information about recurrence, an area in which complexity and uncertainty are inherent.²⁻⁵ Breast cancer survivors are at risk for recurrence and are at greater risk of developing a

second primary breast cancer in the contralateral breast compared to women who have never been diagnosed.^{6,7} Therefore, vigilant breast cancer surveillance in this group is particularly important. Evidence suggests that locally recurrent and second primary breast cancers found at an early stage, specifically those that are noninvasive or characterized by smaller tumor sizes, have a better prognosis compared to cancers detected at a more advanced stage.^{8,9} Early detection also increases the likelihood of achieving disease control, complete remission, or extended survival.⁸⁻¹¹ Evidence-based guidelines for post-treatment breast cancer surveillance have been established by the American Society of Clinical Oncology (ASCO) and include annual mammography and more frequent physical exams.^{11,12} Alarming, studies report racial differences in post-treatment mammography adherence such that African American breast cancer survivors have a lower likelihood of completing consecutive surveillance mammograms over time.^{13,14} It has also been reported that the duration of medical follow-up care for African American survivors is significantly shorter than that of White survivors.¹⁵ These findings suggest that the promotion of

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post-treatment breast cancer surveillance among African American survivors is an area deserving investigation and special efforts.

Survivors in Spirit (SIS) is an intervention that was developed to promote post-treatment breast cancer surveillance among African American breast cancer survivors using a widely applied intervention approach: the involvement of lay health workers. A lay health worker (LHW) has been defined as someone, paid or voluntary, who carries out functions related to health care delivery; is trained in some way in the context of an intervention; and has no formal professional or paraprofessional certificated or degreed tertiary education,¹⁶ presumably in a health-related area or the specific focus of the intervention. The use of LHWs has gained wide recognition as an outreach strategy in breast cancer prevention and control. LHWs have been integral to breast cancer screening interventions in African American communities and have performed a variety of tasks, including church-based telephone counseling;^{17,18} in-home education;^{19,20} community outreach;²⁰ the provision of informal supportive contact with community women in their social networks;²¹⁻²³ and the implementation of structured educational sessions and service as role models in one-on-one and group settings.²⁴⁻²⁶ It is important to note that in almost all of these LHW interventions, the LHWs were peers, ie, individuals similar to the target population ethnically, culturally, linguistically, and/or socioeconomically. Shiner²⁷ notes that the notion of a peer is based on categorizations related to identity and one's affiliation with a group. In the broadest sense, a peer is a similar other or "someone like me." The growing implementation of LHW interventions in breast cancer prevention and control warrants greater report and dissemination of strategies to recruit and train these interventionists. This paper describes the development of the SIS LHW training curriculum and the implementation of the curriculum in New York City as part of a funded randomized controlled trial to test the SIS intervention. To date, SIS represents the only intervention effort focusing specifically on racial disparities in post-treatment breast cancer screening.

MATERIALS AND METHODS

Curriculum Content: Focus and Development

SIS is grounded in the model provided by The Witness Project (WP),^{25,26,28} a breast and cervical cancer education program developed to increase the number of African American women in the general population who participate in regular mammography, clinical breast examination, breast self-examination (BSE), pelvic exams, and Pap tests. Originally developed in Arkansas with a focus on rural African American women, the WP trains breast cancer survivors, referred to as witness role models, to share their own experience of cancer diagnosis and treatment. The program is based, in part, on the African American cultural and spiritual practice of "witnessing," the sharing of personal stories

of struggle, faith, and empowerment. Witness role models also stress the importance of open dialogue about breast cancer in the community in order to promote early detection and prevention. WP programs also include presentations by lay health advisors who describe basic breast cancer facts and statistics, risk factors, specific surveillance modalities, and provide instruction in breast self-exam (BSE). Several early studies of the WP reported significant increases in mammography and the regular practice of BSE from pre- to post-intervention.^{25,26} The WP grew into a national initiative with over 30 replication sites in the United States. As part of replication efforts, data were collected through 25 sites. Across these sites, 401 witness role models and lay health educators reached 10,431 women through WP programs. Key components and criteria of successful replication were established, and data from a subsample of 594 women age 40 and older showed a 43% increase in screening among those who were unscreened or underscreened prior to attending a WP program.²⁹

The SIS curriculum followed this model closely with most of the information derived from an extensive review of related literature. Table 1 presents the components of the SIS curriculum. The development of the SIS LHW training curriculum was also guided by an advisory board that was organized for this purpose. The initial board included 16 people representing diverse backgrounds, including oncologists, breast surgeons, community health activists and educators, and breast cancer survivors. Once the curriculum was drafted, the board was convened to review the curriculum. Advisory board members had the opportunity to critique and provide feedback and make recommendations regarding the format of the training, language and images used, facts provided, and overall impact.

Identification and Recruitment of SIS LHWs

Identification and recruitment of SIS LHWs was based on the WP model and the SIS intervention relies on 2 types of LHW. The first are survivor speakers, African American breast cancer survivors who are individuals most similar to the intervention's target group. The primary role of survivor speakers is to share their personal narratives of cancer diagnosis, treatment, and follow-up care. Using one's own experiences to communicate a message is common and in terms of cancer control, it is suggested that narratives can overcome resistance to adopting information and facilitate processing of information.³⁰ Research focusing on narrative communication in cancer control suggests that, "Cancer survivors' direct experience with the disease and demonstrated success living with cancer makes them especially attractive and credible as messengers of cancer information."³¹

Like the WP, SIS is faith-based and supports expressions of religious belief and spirituality among survivor speakers. This approach is consistent with the findings of Culver and colleagues³² who reported that compared to White breast cancer survivors, African American survivors reported

TABLE 1. Components and Objectives of SIS Training Curriculum

1. Introduction
1.1 Describe SIS' primary goals
1.2 Introduce theoretical and conceptual frameworks that inform SIS
1.3 Describe specific roles of survivor speakers and lay health educators
2. Defining recurrence
2.1 Provide definition of breast cancer recurrence
2.2 Clarify distinction between local, regional, and distant recurrence
3. Epidemiology of breast cancer recurrence
3.1 Present data on incidence of breast cancer recurrence
3.2 Present data on survival following recurrence
3.3 Provide specific data regarding breast cancer recurrence among African American survivors
3.4 Review of risk factors for recurrence
4. ASCO guidelines for post-treatment cancer surveillance
4.1 Present ASCO guidelines
4.2 Describe rationale of guidelines related to physical exam, symptom history, mammography, pap test/pelvic exam, and breast self-examination
4.3 Discuss symptoms of recurrence
4.4 Present data comparing minimal surveillance (ASCO guidelines) with intensive surveillance (radiological and laboratory tests)
5. Second primary breast cancer
5.1 Define second primary breast cancer
5.2 Present data on incidence of second primaries
6. Genetic risk for breast cancer recurrence
6.1 Provide a basic definition of genes and their functions
6.2 Present specific information about BRCA1 and BRCA2
6.3 Identify characteristics of appropriate candidates for BRCA testing
6.4 Present risk of developing a contralateral breast cancer and recurrence among BRCA mutation carriers
6.5 Discussion of higher prevalence of ambiguous BRCA test results among individuals of African descent compared to other groups
6.6 Describe options of genetic counseling and genetic testing
6.7 Describe surveillance options for survivors with a BRCA mutation
7. Psychosocial factors and lifestyle
7.1 Describe data on attitudes and beliefs about post-treatment breast cancer surveillance and follow up care among African American breast cancer survivors
7.2 Review American Cancer Society guidelines for survivors regarding diet and exercise
8. Resources
8.1 Review relevant brochures and handouts from agencies including the National Cancer Institute, Breastcancer.org, the American Cancer Society, and the Susan G. Komen Breast Cancer Foundation.
8.2 Review listing of low-cost and no-cost local sources of medical care in the NYC area
9. Instruction in breast self-examination
9.1 Review issues specific to survivors and BSE including physical and emotional discomfort.
9.2 Teach in the grid or "up-and-down" method of BSE as endorsed by the American Cancer Society and Susan G. Komen Foundation.
10. Primary experiential component
10.1 Survivor speakers structure and practice their testimonies.
10.2 Lay health educators receive additional training in presenting SIS' didactic components and use of flipchart as a presentation tool.
10.3 Conduct a mock presentation.

greater use of religious coping. Additionally, the involvement of breast cancer survivors as interventionists is important, as previous research has identified a range of structural and psychosocial factors that enable and impede surveillance within this population. Enabling factors include support from health care providers, familial relationships, relationships with other survivors, and religious/spiritual faith, whereas barriers include lack of knowledge, cancer fear, and prohibitive medical care costs.³³ Consistent with these findings, survivor speakers are encouraged, as part of their narratives, to describe the ways in which these issues have affected their own participation in post-treatment surveillance. The second type of LHW in SIS is referred to as a lay health educator. Lay health educators serve a more didactic role and provide education about breast cancer recurrence and surveillance.

The recruitment of SIS LHWs focused on African American women. In our initial outreach, we primarily drew upon the resources of the New York City (NYC)-based Witness Project of Harlem (WPH), a replication site of the national Witness Project that is housed in the same institution as SIS. The WPH conducts programs in the NYC metropolitan area as well as other parts of New York state and New Jersey. To recruit for SIS, letters were sent to WPH volunteers and presentations were made at WPH volunteer meetings. Additionally, recruitment letters were sent to individuals on the general WPH mailing list. Outreach was also directed toward other local African American breast cancer survivor groups and networks. These recruitment methods are consistent with the report of a recent review of LHW interventions stating that the 2 most commonly described recruitment methods were word of mouth and the media.³⁴ As a broader empirical issue, the extent to which differences in LHW recruitment strategies affect intervention efficacy are unknown.

Women were considered eligible to be SIS LHWs if they (1) had strong interpersonal communication skills; (2) were ambulatory, with no health concerns that prevent local travel; (3) were accessible by telephone; (4) were at least 21 years old; and (5) were able to read and write. In terms of compensation, LHWs received \$25 for each program they helped to conduct. This amount was intended to reimburse LHWs for any costs incurred through their participation in the intervention, such as transportation or food costs. Jackson and Parks³⁴ reported that more than half of the LHW programs they reviewed offered compensation to their LHWs, ranging from \$5 per intervention to full-time employment and salaries. For SIS, the compensation was modest in order to avoid professionalizing LHWs and compromising their credibility as perceived by community members in terms of allegiance to the community versus allegiance to the research program. In total, 33 women were trained as LHWs (20 lay health educators and 13 survivor speakers). Table 2 includes SIS LHW sociodemographic characteristics. Not surprisingly, the majority of the group reported previous public speaking experience, with approximately half reporting previous involvement with the WPH.

TABLE 2. Sociodemographic Characteristics of SIS LHWs

	%
Type of LHW	
Survivor speaker	39
Lay health educator	61
Age	
20-40 years	15
41-60 years	58
>60 years	18
Not disclosed	9
Currently Employed	
Yes	58
No	42
Education Level	
High school	30
Some college or vocational training	24
Bachelors or graduate degree	46
Past Public Speaking Experience	
Yes	82
No	18

Implementation: SIS Training Format and General Considerations

The primary training component of LHW training was a 5- to 6-hour core group session. These sessions were scheduled either in the evening after work hours or during the weekend. In keeping with SIS as a faith-based program, training sessions always started with group prayer or an inspirational reading. Each trainee was provided with a binder that included a printout of the accompanying PowerPoint training presentation. The binder also included related brochures and pamphlets that audience members would receive (see Table 1). Trainees were asked to review all of these materials. At the end of this initial training session, trainees received a certificate of completion.

The core session included an experiential component focused on rehearsal. Trainees were divided into 2 groups based on their roles. In the first group, survivor speakers focused on their testimonies as part of the SIS presentation. This was facilitated by a worksheet that helped to guide survivor testimonies by focusing on the following areas: specific information about their breast cancer diagnosis and treatment; information provided about post-treatment breast cancer surveillance by healthcare providers; feelings (eg, fear, anxiety) experienced during the first post-treatment mammogram, physical exam, or breast self-examination; coping strategies; changes in perspective and outlook since breast cancer treatment; and personal strategies for continued well-being. During this part of the training, survivor speakers structured and practiced their testimonies to fit a 5- to 10-minute time limit. In the second group, lay health

educators received additional training in presenting SIS' formal didactic components. The primary presentation tool in SIS is a flipchart. The side that faces the audience included illustrations and brief bulleted points for the audience to read. On the side facing the lay health educator, there are highlighted talking points that guide the educator through the presentation.

The experiential component also included pronunciation review such that trainees practiced the correct pronunciation of medical terms that are part of the SIS presentation. This practice was facilitated by a glossary created by SIS staff that presents key words (eg, mastectomy, metastasis) phonetically. After each group completed training tasks separately, they were brought back together in order to conduct a mock presentation. The specific order of an actual SIS presentation is as follows: (1) an LHW leads group in prayer or a devotional/inspirational reading; (2) an LHW provides general introduction to SIS; (3) survivor speakers present their personal testimonies; (4) a review of breast cancer recurrence and surveillance information based on the literature review is discussed by a LHW; (5) a review of resources is presented by a LHW; (6) and a "hands-on" BSE instruction using the grid or "up-and-down" method of BSE, which has also been reported as more effective than circular techniques, is presented by a LHW.³⁵ Following this core training session, each LHW was required to participate in a minimum of 2 individual or small-group training sessions with a SIS staff member in order to strengthen individual presentation skills. These supplemental sessions served as opportunities to practice and refine presentation skills and focus on individual learning needs. LHWs were only allowed to conduct trainings once SIS staff subjectively determined individual readiness.

RESULTS

Impact of LHW Training

In total, 5 SIS training sessions were conducted. The trainees completed a pre-test and post-test to assess changes in knowledge of the content areas reviewed during the SIS training. Table 3 presents the 10 items administered both before and after the training session. In total, 28 trainees completed both the pre-test and post-test. Across 8 of 10 items, there was an increase in the percentage of trainees who correctly responded from pre-test to post-test. There was no change from pre-test to post-test for 2 items. The first, item 5 ("Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.") was the only item that required trainees to recall a specific statistic and this may account for the generally poor performance on this item. The second, item 8 ("Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.") had a very high rate of correct response at both pre-test and post-test. Trainees were also given the opportunity to evaluate their training experience. As

TABLE 3. Pre-test and Post-test Responses

Item	% correct	
	Pre-Test	Post-Test
1. Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	36	54
2. Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	25	82
3. Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	93	96
4. Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	64	96
5. Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	39	39
6. Breast cancer survivors only need to have physical exams about once a year after they have completed breast cancer treatment.	57	79
7. Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	96	100
8. Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	96	96
9. Women diagnosed with breast cancer need to examine their own breasts every day.	25	71
10. Chest pain and problems with breathing can be signs of breast cancer recurrence.	36	86
Mean total correct across all trainees	58.9%	77.9%

shown in Table 4, the trainees gave the training sessions overwhelmingly positive ratings.

Preliminary Evaluation of SIS' Format by Intervention Attendees

As noted earlier, SIS was initially implemented in the context of a funded randomized controlled trial (RCT). Participants were recruited through several methods, including outreach to a pool of "graduates" who completed participation in a larger parent case-control study, through referral from local surgeons and oncologists, and outreach to breast cancer survivor advocacy and self-help groups. Actual enrollment in the study was conducted primarily by African American female research associates. Women were considered eligible for the RCT if they self-identified as African American, were between 20 and 74 years of age, were diagnosed with in situ, stage I, II, or III breast cancer, had no history of cancer prior to their breast cancer diagnosis,

TABLE 4. Trainees' Evaluation of Training Sessions

Item	Yes (%)	Somewhat (%)	No (%)
1. I had a clear understanding of the purpose of the training before I came.	59	32	9
2. The training was well organized.	100	0	0
3. The trainers were prepared.	100	0	0
4. The trainers knew what they were talking about.	100	0	0
5. The trainers said what they had to say so I could understand it.	100	0	0
6. There was enough time to cover the information.	70	18	12
7. I felt comfortable asking questions during the training session.	97	3	0
8. My questions were answered thoroughly and confidently.	97	0	3
9. The slides or visual aids were helpful.	96	4	0
10. The instructor(s) was helpful in coaching me through new skills.	100	0	0
11. I feel good about my ability to apply the new skills and information in teaching others.	93	7	0

and were at least 3 months post-treatment. Table 5 presents sociodemographic variables for the first 20 SIS participants. The majority of participants were African American, unmarried, and reported some college education. Additionally, the majority reported having some form of health insurance coverage.

As part of the SIS program, attendees' evaluations of SIS' format were assessed. Of the women who attended the SIS session, 100% of attendees reported that the presentation was well-organized, felt that presenters knew what they were talking about, agreed that presenters spoke in ways they could understand, agreed that they felt good about

their ability to use what they learned, and agreed that the testimonies of survivors were rated as a very important component of the presentation. Also, 95% of attendees rated the inclusion of African American women as presenters and in materials as very important.

DISCUSSION

Increases in the number of breast cancer survivors in the United States has led to an increase in the number of interventions targeting breast cancer survivors. A number of interventions have been developed to address a multitude of issues faced by cancer survivors, including physical activity and diet,^{36,37} uncertainty management,³⁸ self-management and successful survivorship transition,¹ and physical and psychological functioning.³⁹ However, there are no reports to date describing an intervention to address racial disparities in breast cancer screening among survivors. SIS was developed to address these disparities by focusing on the promotion of post-treatment surveillance specifically among African American breast cancer survivors. A central feature of SIS is the involvement of LHWs as interventionists who were trained to convey complex information about breast cancer recurrence and surveillance. The description of SIS curriculum development and implementation currently presented suggests that LHWs can be successfully prepared to conduct this type of work.

Results of the training evaluation show that exposure to the curriculum resulted in substantial increases of knowledge regarding this topic among the LHW trainees. LHW proficiency was also supported, in part, by the evaluations of SIS' implementation by the target audience of African American survivors, who not only indicated adequate comprehension of SIS' content and confidence that they could apply what was learned, but also indicated that having LHWs, specifically African American female peers, was a very important part of the intervention. Although these findings are suggestive of LHW proficiency, a limitation of the curriculum's implementation was the lack of continued assessment of knowledge over time as well as the absence of the objective assessment of other LHW competencies, such as comfort with SIS vocabulary and use of the flipchart

TABLE 5. Sociodemographic Data on SIS' RCT Participants Who Attended SIS Programs

	N=20 (%)
Age, mean (range), years	58.0 (43-71)
Race/Ethnicity	
Black/African American	70%
Afro Caribbean/West Indian	25%
Other	5%
Marital Status	
Never Married	30%
Married	25%
Divorced/Separated/Widowed	45%
Education	
High school graduate or less	30%
Some college	50%
College graduate and beyond	20%
Currently Employed	
Yes	47%
No	53%
Annual Household Income	
\$39,999 or less	61%
\$40,000 and above	39%
Health Insurance	
Insured	70%
No health insurance	20%
Other	10%

during the presentation. The future implementation of this curriculum should include multiple evaluations of LHW knowledge and skills over time, not only during the training phase but also during later implementation of the intervention in the community. Although this was a limitation, it is important to acknowledge that such LHW proficiency was assessed informally by staff members who continued to work with LHW trainees after the core training session in individual and small-group sessions. The extensive use of rehearsal as an experiential training strategy and mandated follow-up training sessions, in which LHWs were given more specific, individualized feedback were central in establishing LHW readiness.

The findings reveal that SIS demonstrates promise as a community-based intervention to promote breast cancer surveillance. As the RCT is completed, an area of concern is feasibility of implementation. In practice, it takes considerable time to coordinate the logistics of drawing an audience of survivors for a SIS program. This issue has important implications for SIS implementation beyond the research context. The nature of the live SIS presentation requires audiences of survivors who, it may be argued, are most easily found in breast cancer support group settings. Although recent data reveal no racial differences in support group participation, the overall rate of support group participation among survivors is fairly low across race.⁴⁰ If SIS audiences are primarily identified through support groups, there is a risk that the information presented by SIS will be disseminated to a very limited and self-selected group of survivors. The second implementation issue that has emerged is that for each SIS program, a team of 4 to 6 lay health educators has to be assembled to conduct presentations. This is a labor-intensive process that may not be cost-efficient when all expenses are considered (eg, covering costs of transportation, refreshments, etc.) These challenges are currently being addressed in a separate research study focusing on the conversion of the live SIS program into a DVD, a medium that is more easily disseminated to individual breast cancer survivors. Recent results of a national survey by the Pew Research Center for the People & the Press indicated that 86% of American households own a DVD player, suggesting that it is accessible technology.⁴¹ Such a DVD intervention could share elements of the live SIS program in terms of specific content, presentation by breast cancer survivors and other lay health educators, and culturally sensitive elements. In addition to addressing the problems described above, a SIS-DVD would have the advantages of (1) allowing a survivor to receive SIS content without necessarily having to travel outside of her home; (2) allowing review of the content at a comfortable pace for maximum comprehension; (3) allowing review of content sections in whatever order is desired because most DVDs are menu-driven and their content available in discrete sections; and (4) allowing multiple viewings during the post-treatment period. The creation of a SIS-DVD would also increase the likelihood that an overall greater number of African American breast

cancer survivors will be reached and informed. This medium, as well as others, are important areas of investigation in efforts to promote post-treatment breast cancer surveillance.

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